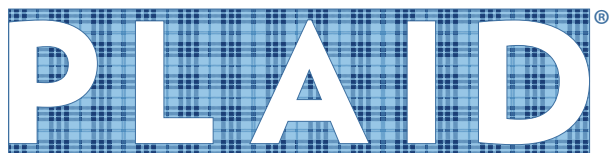


NARRATIVE INQUIRY IN DIABETES RESEARCH:

Illuminating the psychosocial aspects of diabetes

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DOI:
<http://dx.doi.org/10.17125/plaid.2016.60>



People Living with And Inspired by Diabetes

ABSTRACT

Diabetes self-care is integrally and holistically connected with everyday life, but research prior to 2008 primarily used surveys and interviews to understand the psychosocial aspects of the illness experience. Narrative research methods, in contrast, can give greater attention to connection and context. The aim of this paper is:

1. to review empirical studies using narrative methods to understand the insights narrative inquiry can offer into diabetes psychosocial experiences and concerns; and
2. to provide methodological recommendations for researchers interested in using narrative inquiry.

Twelve published empirical articles using narrative inquiry in diabetes research were reviewed, and themes were identified using content analysis.

Findings from the analysis of these 12 studies suggested narrative inquiry can offer insight into psychosocial experiences and concerns by:

1. illuminating how those with diabetes think about and make meaning of this chronic disease;
2. articulating the social contexts of their experiences; and
3. making visible the self-care and treatment challenges they face.

Insights from narrative inquiry could enhance diabetes self-management education and support such as encouraging patients to express their experiences as stories to make their challenges visible.



INTRODUCTION

Diabetes is a major public health burden and growing national epidemic. Nearly 10% of the United States' population lives with this chronic health condition [1]. It is a demanding self-care disease that requires ongoing attention and complicated treatment. The "cluster of daily behaviors" [2] necessary to manage diabetes includes regular blood glucose monitoring, medication adherence, physical activity, and a healthy diet. People with diabetes may lack the information, education, or problem-solving skills necessary to balance these self-care behaviors and integrate them with daily life [3, 4]. The daily struggles and unpredictable outcomes of self-care, moreover, may impact psychosocial adjustment in these individuals [5, 6, 7]. Understanding how people with diabetes comprehend and make sense of their experiences may inform interventions and suggest changes in the types and nature of psychological, social, and self-management support provided to them.

Evidence suggests that psychosocial factors influence health outcomes. Self-efficacy, social support, and diabetes distress are common in literature on the experiences of people with diabetes. Self-efficacy has been positively associated with glycemic control, medication adherence, and self-care [8, 9, 10, 11]; social support has been positively related to self-care [8, 9]; and distress has been associated with suboptimal self-care across multiple countries [4, 12]. Psychosocial support for people with diabetes remains inadequate [4, 13] despite evidence that psychosocial factors influence health outcomes and appear modifiable through intervention [5, 14, 15]. A greater understanding of how people with diabetes comprehend and make sense of their psychosocial experiences and concerns could result in improved outcomes and self-care.

One way to better understand the psychosocial experiences of human beings is through narrative inquiry [16, 17]. Narratives articulate how experiences are understood rather than how they actually happened. Narrative inquiry is a qualitative methodology that studies stories or storied text [18]. Telling stories is an attempt to organize experiences and make sense of events and experiences. The stories people tell include what they choose to share with the listener and how they connect the multiple components of experience; plots, characters, scenes, and motives are connected into comprehensive representations of experience. Narrative research attempts to analyze whole experiences rather than fragmenting accounts into discursive units or thematic categories. This holistic focus makes narrative

inquiry well-suited to study the complicated intersection of psychosocial experience with daily life.

The two-fold aim of this paper is to review empirical studies using narrative methods to understand the diabetes experience in order to identify insights these methods can offer, and to provide recommendations for researchers interested in using narrative inquiry. To accomplish these aims, the authors present three intersecting themes that represent the insights narrative inquiry can offer into the psychological and social aspects of living with diabetes. The themes overlap but are presented separately to highlight the distinct contributions narrative can make to diabetes research. Excerpts of participants' stories from the findings of published narrative studies help illustrate the themes. Narrative research on diabetes can offer insight into psychosocial experiences and concerns by: 1) illuminating how those with diabetes think about and make meaning of this chronic disease; 2) articulating the social contexts of their diabetes experiences; and 3) making visible the self-care and treatment challenges they face.

METHODS

Empirical articles that used narrative methods to investigate diabetes were identified for review. The studies in this review: 1) represented original research; 2) were published in a peer-reviewed academic journal; 3) had diabetes as a primary subject; and 4) incorporated narrative inquiry in data collection and/or analysis. Four academic databases (PubMed, PsycINFO, Scopus, and Web of Science) were searched over seven months (February through August, 2014) for diabetes studies employing narrative research methods (data collection, analysis, or both). Search terms included pairing "diabetes" with "narrative methodology," "narrative study," "narrative method," "narrative research," "narration," "personal narratives," and "narrative inquiry." Additional studies were identified in bibliographies of key studies and journal indexes and through consultation with a health sciences librarian. Consultation with researchers experienced in narrative methodologies also guided data collection.

Twelve articles were identified and subsequently examined for concepts and themes using qualitative content analysis. [19]. Each article was read multiple times by the first author. Reflective notes were recorded in a research journal that commented on narrative characteristics, connections to literature, and tentative patterns. Research findings

and data from the 12 articles were examined for recurring concepts. QSR NVivo 10 software facilitated an emergent coding process. Final codes represented aspects of diabetes psychosocial experiences and concerns. Codes were combined into preliminary themes that were shared with colleagues through informal academic presentations, and feedback was incorporated into the final representations.

RESULTS

The twelve previously mentioned articles reported results from eleven unique studies (Table 1). With one exception, all were published in the last seven years (2008-2014). The studies sampled people with either type 1 (T1D; $n = 5$) or type 2 diabetes (T2D; $n = 6$). One study included patients with either T2D or chronic pain. Ten of the eleven studies sampled adults over age 18; the one exception sampled adolescents age 13-18. Two studies recruited young (age 21-30) or emerging (age 19-25) adults. Among all the studies, the average age of participants ranged from 16.5 to 62.7. Five studies originated in Europe (England = 2, Italy = 2, Germany = 1); five were conducted in the United States (Los Angeles, Boston, Pennsylvania, Arkansas delta, rural Appalachia); and one took place in Canada. Nearly all the studies explored aspects of diabetes self-care. Four studies considered the meaning-making and healing consequences of storytelling, and two of these four incorporated narrative self-writing or autobiography.

Findings from the analysis of these studies showed how narrative research methods can offer insight into diabetes psychosocial experiences and concerns by: 1) illuminating how those with diabetes think about and make meaning of this chronic disease, 2) articulating the social contexts of their diabetes experiences, and 3) making visible the self-care and treatment challenges they face. Altogether, these themes demonstrate how narrative inquiry offers a holistic understanding of diabetes psychosocial experiences and concerns.

Illuminating How People Think About and Make Meaning of Diabetes

Narrative research can illuminate how people think about and make meaning of their illness. Gomersall, Madill, and Summers [20], for example, used a biographic-narrative method to explore the inner dialogues of women with poorly controlled type 2 diabetes. Eight women were interviewed and prompted to narrate their life stories and experiences

since diagnosis. Key moments, defined as emotionally-laden stories, were analyzed using a dialogical narrative approach. One woman described her thoughts about self-care: “So you’re telling me ‘Rachel you’ve got diabetes. Now you’ve got to learn to control this sugar. You need to cut down. You need to cut these things out.’ And I think, ‘Who are you to tell me what to do?’” The excerpt from this woman’s life story demonstrates her inner struggle to accept diabetes and the self-care it requires.

Stuckey and Tisdell [21] found similar conflict in the thoughts of people with diabetes. In this narrative interview study of how adults make meaning of type 1 diabetes, participants described their experiences living with and managing diabetes. Interview transcripts were summarized in story form and then analyzed thematically. Women in this study narrated negative and positive thoughts and feelings about their illness. One woman described frustration over low blood glucose: “At 2:00 am, who am I going to get mad at? . . . it’s a constant reminder . . . It’s part of me, and it’s easy to be stubborn and angry and say, ‘I’m not going to take care of it anymore,’ but that would be more hurtful than helping” [21]. Positive thoughts also emerged about diabetes as some participants considered negative aspects optimistically. One woman thought “a key to being whole with diabetes” was to be positive [21]. Endurance sustained the women in this study through difficult times. Findings from these narrative interview studies demonstrate inner struggles and conflicting thoughts about diabetes and provide evidence that narrative inquiry can illuminate how people think about diabetes.

In addition to narrative interviews, narrative self-writing can be used as an approach to understand the thoughts of people with diabetes. This method includes autobiographical writing in journals and diaries. Piana et al. [22] conducted a qualitative feasibility study to test an autobiographical narrative approach in adolescents with diabetes. Thirty adolescents (age 15-18) with type 1 diabetes completed daily self-writing proposals during a nine-day summer camp, and semi-structured questionnaires were administered to elicit their views of the writing process. The researchers found that narrative self-writing provided a way to make meaning of diabetes, and it facilitated changes in the adolescents’ relationships with diabetes. One adolescent expressed this transition in writing: “Before, I felt a certain anger and negativity in facing up to it, this has now been removed” [22]. Another adolescent commented, “I started to come to terms with it and stop thinking, why just me? Well, since it happened to me and so many others, we must learn to

<i>Source</i>	<i>Location</i>	<i>Purpose</i>	<i>Sample</i>	<i>Diabetes Type</i>	<i>Collection</i>	<i>Analysis</i>
1. Barton [27]	Canada	Expand understanding of diabetes within a specific cultural context	Persons of Nuxalk ancestry (N = 4)	Type 2	Life narratives	Analyzed stories at universal & local levels over a number of years
2. Bhattacharya [38]	USA	Understand spiritual issues that may hinder or promote self-management	African American men & women (N = 31)	Type 2	Semi-structured interviews	Grounded theory
3. Gomersall et al. [20]	England	Understand how women sought to make sense of life with diabetes	Women age 45-71 (N = 8)	Type 2	Biographical Narrative Interview Method	Dialogical analysis
4. Graffigna et al. [23]	Italy	Explore reasons for disengagement	Men & women	Type 2	Narrative diaries & in-depth semi-structured interviews	Interpretive content analysis
5. Lucius-Hoene, Thiele, Breuning, & Haug [45]	Germany	Understand patients' experiences concerning their doctors	Men & women with either diabetes (N = 26) or chronic pain (N = 30)	Type 2	In-depth interviews	Positioning & narrative analyses
6. Manoogian et al. [28]	USA	Explore family experience of type 2 diabetes	Men & women with diabetes & family support members, 40 Family dyads (N = 80)	Type 2	Focus groups, individual interviews & family interviews	Constant comparative analysis
7. Piana, et al. [22]	Italy	Observe effects of narrative-autobiographical approach on adolescents' self-awareness, concern for self-care, and well-being	Adolescents age 13-18 attending a 9-day summer camp (N = 94)	Type 1	Daily self-writing proposals and semi-structured questionnaires	Content analysis
8. Pyatak, et al. [30]	USA	Explore motivations underlying nonadherent treatment decisions made by young adults with type 1	Emerging adults age 19-25 years (N = 8)	Type 1	Semi-structured interviews	Narrative thematic analysis
9. Ritholz & Jacobson [31]	USA	Increase understanding of the everyday experiences of those with type 1	Men & women age 21-30 (N = 20)	Type 1	Semi-structured interviews	Standard qualitative methods
10. Snow et al. [34]a	UK	Explore impact of patient education on their lives	Men & women age 20s to 60s (N = 21)	Type 1	Longitudinal semi-structured interviews & observations	Narrative thematic & structural analyses
11. Snow, Sandall, & Humphrey [46]a	UK	Explore the impact of education and target-setting on life stories	Men & women age 20s to 60s (N = 21)	Type 1	Longitudinal semi-structured interviews & observations	Narrative thematic & structural analyses
12. Stuckey & Tisdell [21]	USA	Explore meaning that patients ascribe to having diabetes	27-57 (N = 8)	Type 1	Interviews	Narrative & content analyses

a Snow et al. [34] and Snow et al. [46] report unique findings from the same study.

accept it and to live with it” [22]. In this study, narrative self-writing illuminated adolescents’ evolving thoughts about diabetes and increased their coping capacities.

Graffigna and colleagues [23] took a similar approach in their study on patient engagement and diabetes self-care. Adults with uncontrolled type 2 diabetes (defined as A1C > 8) each kept a diary for one week. They wrote stories about their experiences with self-care at diagnosis and in daily life. The stories illuminated how the participants gave meaning to diabetes, its management, and its connections to daily life. These findings were interpreted to identify and explain factors hindering engagement in diabetes self-care.

Articulating Social Contexts of Diabetes

As discussed previously, diabetes narrative studies have been used to illuminate how people think about and make meaning of diabetes. There is, however, a need to go “further outward into the social” when considering illness experiences [6]. Family and friends have been found to play a significant role in diabetes self-management [24]. The second theme demonstrates how narrative research can be used to describe diabetes experiences within these social contexts.

Family involvement in diabetes self-care has been well-documented [25, 26]. Findings from narrative studies can articulate the relationships between family and diabetes self-care. A life narrative study by Barton [27], for example, considered the cultural contexts of diabetes. The participants included four adults of Nuxalk ancestry living in Canada, and multiple stories were collected from each adult. Findings from this study described the role of family elders in diabetes experiences; participants looked to elders for knowledge and advice about diabetes. Other narrative studies have also described family roles and influences on perceptions and behaviors [28, 21]. Manoogian et al. [28] investigated diabetes experiences in rural Appalachia through a multi-phase narrative study of people with type 2 diabetes and their families. Data were collected through focus groups, individual interviews, and family interviews. Participants from this study described how family storytelling shaped diabetes beliefs and behaviors. Family elders both shared and silenced stories about diabetes within their families; stories were shared to encourage positive self-care behaviors and silenced to protect younger family members from distressing storylines.

Family involvement in an individual’s diabetes self-care may not always be supportive [29]. Results from a narrative

study by Stuckey and Tisdell [21] described family strain in which women with type 1 diabetes were prompted to narrate their diabetes experiences during interviews. One woman described an incident in which she added jelly to a sandwich and was caught by her father. Her father told her mother, and she felt guilty because she did not adhere to her diet. While family strain is not new to the diabetes literature, narrative methodologies offer a deeper understanding by organizing such experiences as stories. These stories combine family members, plots, and motives into holistic representations that can more clearly illustrate how experiences are understood.

Narrative inquiry can also provide insight into the role of friends [30, 31]. A narrative study investigating emerging adults’ (age 19-25) perspectives on nonadherence to diabetes self-care discovered social support problems [30]. They were adversely influenced by friends. Perceived peer pressure challenged self-care behaviors among young adults in this study. For example, one participant described: “We’ll be out to dinner and I’ll check [my blood sugar] under the table, and you can tell the conversation has stopped because everyone is staring. And I’m like, ‘What are you doing? This is weird’” [30]. Ritholz and Jacobson [31] identified another social challenge in their narrative study of diabetes hypoglycemic experiences. Through semi-structured interviews, the researchers elicited stories of hypoglycemic episodes from adults with type 1 diabetes, and interpersonal conflict was a salient theme. One woman described conflict with her boyfriend:

My boyfriend has had to deal with several [hypoglycemic episodes] recently. . . . I’d be upset that he recognized that I was low and I didn’t, and that he was in control. And all sorts of issues that are tenuous in our relationship would start to come up. And I’d be very mean to him and shun him and tell him to just go away. Let me deal with this on my own. He’d feel incredibly hurt. And then I’d reject treatment from him, and he’d feel like I was calling our whole relationship off. [31]

This story excerpt is an example of how women in this study at times had difficulty accepting help during a hypoglycemic episode.

Explaining Self-Care and Treatment Challenges

Psychosocial barriers to diabetes self-care include inadequate self-efficacy [32]; uncertainty about self-care regimens and disease identities [3, 33]; and inadequate family support

systems [32]. Diabetes narrative studies can illuminate how people think about and make meaning of diabetes in social contexts, and they can also provide explanations for barriers to self-care.

Two narrative studies explored disengagement in diabetes self-care and treatment [23, 30]. Participants from these studies reported uncertainty, psychosocial adjustment, and weariness. The stories of adults with uncontrolled type 2 diabetes (HbA1c > 8) described uncertainty about doctors' instructions [23]. They noted that the doctor instructions were too abstract, and information was ineffective and incomplete. The participants articulated a need for specific examples of self-care requirements. For example, "The doctor told me that I have to do some physical activity, but he didn't advise on the kind of exercises I should do" [23]. Shifting blood glucose targets were a source of uncertainty among young adults (ages 19-25) with type 1 diabetes enrolled in higher education [30]. The standards for blood glucose control shift as children transition from youth to adulthood and encounter more intensive therapies. One young adult's story described her frustration: "When I was diagnosed at age 14, I was in pretty good control by whatever standards they were using at the time . . . but more and more they have better standards" [30]. Fluctuating treatment standards appeared to overwhelm young adults in this study.

Findings from the narrative studies identified psychosocial adjustment as another reason for disengagement from self-care. A narrative study using diaries to collect stories about diabetes management found that self-care practices were a constant reminder of their illness. Adults with uncontrolled type 2 diabetes in this study were reluctant to accept a disease identity and thus avoided health behaviors [23]. Adjustment issues for young adults related to social pressures [30]. Anxiety and embarrassment explained their non-adherent treatment decisions around friends. Weariness was an additional challenge to engagement with self-care. A female with type 2 diabetes described feelings of tiredness:

I feel tired and without motivation. When I am in control, I achieve better results. In that case, I feel extremely happy and I feel like I can succeed in managing the disease. I think motivation is key. It is hard, but I have to find motivation. [23].

In addition to concerns related to uncertainty, adjustment, and weariness, a longitudinal narrative interview study found that tension with healthcare professionals complicated diabetes self-care [34]. Participants were adults with

type 1 diabetes completing a patient education course in the United Kingdom. Narrative interviews were used to collect stories about the impact of the course on self-care in daily life. Open-ended questions prompted descriptions of interactions with family, friends, and healthcare professionals following the course. Many participants reported having more knowledge than their primary care providers, and health care professionals were uncomfortable with their new education. One participant was denied additional testing strips, for example, because a health professional deemed them unnecessary. A lack of provider trust was an obstacle to self-care.

Findings from this third category of narrative studies illustrate the daily challenges people face related to self-care and treatment. Uncertainty, psychosocial adjustment, weariness, and tension with healthcare professionals were identified and explained through narrative representations of experience.

DISCUSSION

This paper reviewed the empirical literature that uses narrative method to understand what insights narrative inquiry can offer into diabetes psychosocial experiences and concerns. The results from this analysis suggest that narrative can offer insight into diabetes psychosocial experiences and concerns by illuminating thinking processes, social contexts, and self-care challenges.

Diabetes research has primarily used quantitative surveys [35], focus groups [28, 36], and interviews [37] to understand the psychosocial aspects of illness experience and self-care. Surveys provide useful information about variables and concepts but lack connections and context from the patient's point of view. Focus groups and interviews elicit contextual data, but transcripts have commonly been analyzed using content analysis, a method that fragments experiences into codes and categories. Diabetes self-care is integrally and holistically connected with everyday life, and narrative research methods attend to interconnectedness and context. The stories people share include how they connect the multiple aspects of their experiences. These factors can be represented as whole, rather than fragmented, accounts.

Current diabetes narrative research, however, does not always take this approach. Some studies analyzed narrative material using content analysis [23] and grounded theory [38], approaches that continue to fragment experiences into codes and categories. Two studies described holistic approaches

that could offer deeper understanding and provide models for future research. Snow and colleagues [34] coded whole stories by theme and created a summary document for each story to enable comparison across participants. Similarly, Stuckey and Tisdell [21] summarized interview transcripts in story form. In both cases, whole stories were preserved rather than fragmented into categories and codes.

Narrative analysis can look at themes and structure. Themes describe single narrative accounts and structure considers how a story is arranged and told. Narratives can be collected in natural conversations or solicited in interviews and writing. Narrative interviews focus on plots, characters, scenes, and motives and the connections between these components. A narrative interview may begin with “tell me about a time . . .” and follow up with “what happened next?” or “who was there?” Narrative writing includes journals, letters, and autobiography.

Limitations to the use of narrative research methods relate to study design. Interviews were a primary data collection tool in the studies reviewed here, but the ability of participants to narrate stories could have limited the narrative approach. Not everyone is a natural storyteller, and the stories people share in interviews may lack chronology and coherency. Storytelling is, however, considered a common human behavior [39], and people may provide more information through storytelling than through traditional interview formats. A second limitation was the cross-sectional study design of narrative studies. Because psychosocial experiences are temporal and shifting, analysis of people’s experiences at one point in time limits our understanding of psychosocial concerns. Longitudinal designs, however, are possible in narrative inquiry. For example, one study utilized a series of six interviews to examine adherence and decision-making in the everyday lives of emerging adults with type 1 diabetes [30]. A third limitation relates to generalizability. Narrative data present specific themes and concepts and are not meant to generalize to a population. Narration does, however, provide unique contextual information about diabetes psychosocial experiences.

Implications for Practice

Psychosocial support for people with diabetes remains inadequate [4, 13]. Narrative inquiry is well positioned to illuminate the emotions, contexts, and challenges of diabetes. These insights could inform interventions and enhance diabetes self-management education (DSME) and support. The national standards for DSME recommend tailored curriculum to meet individual needs. The curric-

ulum includes personal strategies to address psychosocial issues and concerns [40]. Narrative methods can provide insight into these issues because people choose to narrate what is important to them. Thus, stories can illuminate the salient concerns of people with diabetes. Educators and instructors could use this knowledge to create tailored curricula to meet the individualized needs of people with diabetes leading to improved health and quality of life.

Narrative approaches to diabetes research could also suggest changes in the types and nature of psychological, social, and self-management support and thus increase the options for patient-centered care. DSME, for example, could incorporate storytelling or autobiographical self-writing to facilitate meaning making. Patients could be taught to organize and express their experiences as stories, making visible the self-care and treatment challenges they face. Piana et al. [22], for instance, observed the effect of a narrative-autobiographical approach on adolescents’ self-awareness, concern for self-care, and well-being. The integration of biography allowed adolescents in this study to improve self-efficacy and responsibility for self-care. Narrative reports may also facilitate conversation in clinic appointments; patients may describe signs and symptoms in story form. A person with diabetes, for example, may describe what happened before and after a mild hypoglycemic episode, who was present, and what actions were taken. These stories may open conversation about disease self-management and provide enhanced support without additional resources. Patients could also share stories with family members and friends to communicate their needs and foster supportive relationships. These examples illustrate the potential of storytelling and self-writing to support psychosocial needs in patient-centered care.

In addition to sharing stories to facilitate meaning making in patient-centered care, DSME could incorporate patient success stories to motivate others. This is particularly important since patient perception influences diabetes self-management [14, 41]. Identification with characters in a story may affect individuals’ health attitudes and beliefs [42]. For example, an educational intervention using African American patients’ success stories about hypertension demonstrated the feasibility of creating stories that meet scientific goals and resonate with patients. [43]. As another example, cancer survivors shared stories about their experiences with other women in a community- and church-based program promoting self-efficacy and screening behaviors. Screening behaviors among these women increased from pre- to post-exposure [44].

In conclusion, narrative inquiry offers a holistic understanding of diabetes psychosocial experiences and concerns. Findings from empirical studies which use narrative methods could inform interventions and suggest changes in the types and nature of support provided to people with diabetes.

CONFLICT OF INTEREST DISCLOSURES

The authors have completed and submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest. The authors report no potential conflict of interests relevant to this article.

ACKNOWLEDGEMENTS

The authors wish to thank Natalia Piana, Healthy Lifestyle Institute, C.U.R.I.A.M.O, University of Perugia, Italy, and Heather Stuckey, Penn State College of Medicine, Hershey, PA, USA, for their valuable insight and encouragement. We also wish to thank Delia B. Allen, University of Georgia, USA, for formatting assistance.

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