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Voice of the patient: people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) share in their own words

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Abstract

Background: Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a serious, debilitating illness affecting millions of people worldwide. Patients with ME/CFS often feel misunderstood and report facing barriers to healthcare utilization.

Objective: We report on a Voice of the Patient (VOP) series that used tenets from photovoice and hermeneutic phenomenology methods. The approach prioritized respecting and engaging patients as they share individual experiences of living with ME/CFS.

Methods: We developed a 5-step process that could be replicated for interviewing patients in their own words. The process prioritized respecting patients while developing, documenting, and sharing individual accounts of living with ME/CFS. The standardized process for gathering each VOP story enabled individuals to share and participate on their own terms.

Results: Over four years, eight VOP stories were completed and posted on CDC's ME/CFS website. The stories received over 196,000 page views. Each story was completed

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Disclosure statement

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in approximately six months. Participants expressed gratitude for the opportunity to share experiences and were appreciative of the process that involved them in the development of stories.

Conclusions: Qualitative methods guided the process for participants taking a central role in sharing stories, which in turn may help educate about patient experiences with ME/CFS. Standardization of steps enabled consistency and transparency. Building flexibility into the process allowed interviewing a range of people with ME/CFS (i.e. bed bound to working) and enabled patients to give narratives in their voice. This process may help to share experiences of people with other chronic diseases or infection associated chronic conditions.

Keywords

Myalgic encephalomyelitis/ chronic fatigue syndrome (ME/CFS); Voice of the Patient (VOP); Qualitative methods

Introduction

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a serious chronic illness that affects the quality of life of patients, caregivers, and family members. People with ME/ CFS experience three primary symptoms: a reduction in pre-illness level of activity accompanied by fatigue, not alleviated by rest, that is present more than 6 months; post-exertional malaise; and unrefreshing sleep [1]. In addition, they must experience at least one of the two following manifestations: cognitive impairment or orthostatic intolerance [1]. Between 836,000 and 3.3 million adults in the U.S. and millions more worldwide are affected [1–3]. Many people with ME/CFS have trouble obtaining a diagnosis and feel as if healthcare providers do not take their symptoms seriously [1]. In addition, many people seeking healthcare for ME/CFS symptoms report barriers to healthcare utilization [4]. The lack of diagnosis, or length of time it takes to obtain a diagnosis, may contribute to frustration and increased misunderstanding among the community of people with ME/ CFS, friends, and families. Many patients with ME/CFS feel misunderstood and belittled by the medical community [5]. Sharing a personal story may help embody empathy for those who are not familiar with the illness and educate healthcare providers about the patient experience with an illness [6].

The field of public health has used the technique of photovoice to assist individuals in being heard about health issues [7]. Photovoice is a form of health promotion in which individuals tell their story by taking pictures from their viewpoint, in their environment. These photos, as taken by the individual, tell a story and illustrate the problem or issue that contributes to the larger health issue from the patient perspective [8]. This method is sometimes thought of as stimulating or fostering social change by raising community awareness and engagement to the issue [7–11]. Another useful method to capture an individual's perspective is hermeneutic phenomenology (hermeneutics is the theory and methodology of interpretation) [12–14]. As described by Fuster, 'It is based on the study of life experiences, regarding an event, from the subject's perspective' (p. 217) [13]. Hermeneutics enables the individual's views of lived experiences and reflection of their interpretation to bring more understanding of their perspective. Tenets from both methods permit individuals to share their unaltered view of life events.

The Voice of the Patient (VOP) is a technique that has been used in health services research to improve healthcare and patient outcomes [15,16]. Hearing about a patient's experience with their illness can help improve the types of services needed for certain populations and that in turn could lead to better health outcomes, and possibly identify the need for new or additional services. For example, as part of a series in 'Patient- Focused Drug Development,' the Food and Drug Administration (FDA) held a meeting to look at possible drug therapies for ME/CFS [17] in 2013. In the FDA's VOP meeting for ME/CFS, the discussion focused a priori on: '1) disease symptoms and daily impacts, and 2) patients' perspectives on current approaches to treating ME/CFS' (p. 3) [17]. Patients and patient representatives shared comments through a panel format and an FDA facilitator further welcomed input from patients in the audience [17]. This model allowed the FDA to hear directly from patients and use the feedback as it embarked in its role in drug development. However, patients gave comments in a public panel format followed by a facilitated discussion, which may not have captured personal narratives [17]. In addition, some patients may not have felt comfortable sharing their personal experience in this format.

In our project, we expanded the VOP for people with ME/CFS by using tenets from photovoice and hermeneutic phenomenology. The application of these qualitative methods aimed to produce a prototype for developing ME/CFS VOP stories in which patients or family members are empowered to direct the interview by telling about their illness experiences in their own voice and importantly in their own words. Further, these stories aim to raise awareness about ME/CFS, foster social change in how people with ME/CFS are viewed, and allow patients with ME/CFS to educate the public and healthcare professionals about the illness in their own words. We report on an innovative project that considered people with ME/CFS, or caregivers, as partners in the effort to systematically tell about the illness experiences.

Methods

The ME/CFS VOP stories are grounded in tenets from qualitative research methods from photovoice and hermeneutic phenomenology [7,12,13]. Photovoice helps represent a person's individual perspective process using photos taken by the individual behind the camera [10]. We adapted the concept of the individual driving and partnering in the interview process to VOP story development. We further used the tenet from hermeneutic phenomenology to uncover the unique personal experiences lived by people who experience their story, and in this case, the experience of living with ME/CFS [14]. Using these tenets to guide the five-step interview process allows the participant and interviewer to join together to capture individual experiences while focusing on the partnership with the participant and prioritizing the patient or caregiver perspective: their spoken words, how they choose to tell the story, and details important to them. This activity was reviewed by the Centers for Disease Control and Prevention (CDC) and was conducted consistent with applicable federal law and CDC policy. We developed VOP stories by the following five step process.

Participant selection

The CDC ME/CFS team met periodically throughout 2017–2021 to purposefully generate a list of potential names for new VOP stories. At the start of the project, the team discussed inclusion of a diverse set of patients. The intentional inclusion of a diverse set of patients with ME/CFS is important to people with ME/CFS and hearing from a wide range of people with the illness broadens the scope of message. This is especially important for ME/CFS as the illness does not affect everyone the same way. While patients share some symptoms such as fatigue, post-exertional malaise, sleep problems or trouble concentrating (as defined by 2015 Institute of Medicine (IOM) case definition) [1], additional symptoms are frequently reported, and patients could be at different stages in their illness and vary in the severity of their illness.

ME/CFS affects people of all racial/ethnic and socio-demographic backgrounds and people of all ages. While found in higher rates among women, men are also affected. Potential participants were identified through word of mouth and referrals from healthcare providers. In some cases, the team turned towards people who had reached out to CDC with questions about ME/CFS to assess their interest in participation. The goal was to develop and finalize two VOP stories per calendar year.

Once people were selected, the interviewer reached out to extend an invitation and explain how the interview would work (i.e. describe the 5-step process). The goal of the project was to post each story anonymously on CDC's ME/CFS website. We approached 10 people about participating in the interviews. Eight people accepted the invitation for an interview. Two people did not feel comfortable participating and declined to be interviewed for the project. Once a person accepted the invitation to participate, the standardized five-step process was implemented. Participants are told that their personal information would be kept anonymous and that they could choose a 'name' for the story. Compensation was not provided.

Documenting the story

Early in the process we decided not to record audio or videotape the interviews for VOP stories to protect the anonymity of patients or family members who participated in the project. The interviewer took handwritten notes in the conversations. In addition to maintaining confidentiality, this approach also allows for a more natural feel for both the interviewer and interviewee. The person who tells their story is more relaxed and does not have concerns about someone, other than the interviewer, hearing their interview. The literature supports not recording interviews as it may provide a neutral environment or space for an interview may contribute to the interviewee feeling more comfortable, leading to better interview [18].

CDC's ME/CFS team decided at the start of the project not to include identifying information such as names of providers, medications, or clinics/hospitals. As such, while these names may have been mentioned in the interview and recorded in the notes, they were not used in the final piece. This allowed the patient/caregivers to tell their story in a fluent way without having to think about withholding names and places.

Respecting the participant

Patients with ME/CFS, or caregivers, who participate in the VOP project volunteer their time to share their experiences. We made decisions to recognize and respect the time and effort that patients and their families have to give to the interview process. We are aware that patients with ME/CFS can have flare up of symptoms that may interfere with their ability to conduct activities of daily living, and this includes time spent on an interview. While caregivers or family members did not necessarily have ME/CFS themselves, they have experienced difficult times in caring for someone with ME/CFS or just watching a loved one with the illness. Therefore, we implemented a flexible interview schedule that was guided primarily by the participant. We explained to participants that while interviews are scheduled to last between 45 min and one hour, there was flexibility in rescheduling or conducting the interview in two or three time slots. Further, allowing flexibility in scheduling may help to reduce stress and allows patients' management of symptoms on their own timeframe. Finally, this recognition reinforces their role in driving the process as a partner.

VOP story development

The story being told by a patient with ME/CFS or caregiver of someone with ME/CFS is driven by the interview. The interviewer has a set of questions (see Table 1) to guide the process, but as the interview progresses it is the person telling the story who directs the storyline. Participants are offered the opportunity to see the guide in advance.

Based on the notes taken during the interview, the interviewer drafts the story by weaving together the comments and thoughts shared throughout the interview. Remaining true to the qualitative process, the written story is developed using the actual words and phrases spoken by the interviewee. Once the story is written, the draft is given to the person who was interviewed who then has the opportunity to review and edit the story. As part of this process, the person telling their story is told that they can make edits, add or delete items. For example, if someone forgot an important detail, he/she is encouraged to add it in. In some cases, there may be several drafts of the story before it is finalized but these steps are important to the integrity of the story development.

Sharing the story

The person who shares their story is involved in approving or identifying an accompanying photo for the website. The theme of the photo often has personal meaning for the person telling their story. In addition, unless the person wishes to use their own name, a pseudonym name is chosen for the story.

Results

Over four years, we developed and posted eight ME/CFS VOP stories, meeting our goal of posting two stories per calendar year. These stories can be found on CDC's ME/CFS website, in the Living with ME/CFS section (<https://www.cdc.gov/me-cfs/living-with/index.html> – some stories have been archived but links to those stories are provided on the same page under Resources). The stories are spaced out by approximately 6 months, which allowed time for completion of the five-step process. In some instances, a VOP story

was completed in as little as 4 months while others took up to 9 months. The approximate 6-month time period to complete the process allowed flexibility for patients, whose symptoms influenced the pace (for example, scheduling of dates and times, rescheduling, interviewing, and follow-up interview if needed). In addition, it honored the draft review stage, which included edits and further communication if needed. The five-step process allows for consistency in developing each story yet allows flexibility that enables individuals to share their unique perspective of living with ME/CFS in their own words.

Participant selection

Inclusion of a diverse group of people with ME/CFS was a primary goal. We achieved this goal by including women and men, people with different ethnic and racial backgrounds, a range of ages, employed people with ME/CFS, homebound people with ME/CFS, caregivers, and families. For example, we heard from a father talking about his daughter with ME/CFS, a mother and son who both suffer from the illness, a person who has been home-bound with ME/CFS, and a wife and husband.

Patients with ME/CFS who participated were also diverse in terms of age, and race and ethnicity. However, if a participant did not disclose demographic information in an organic sense, it was not written into the story, and demographics were not tabulated. In all but one case, the names of the people participating in the project were changed to protect identity (one participant chose to use her first name; no last names were used).

Documenting the story

As planned, all of the interviews were conducted by telephone and were not recorded. The interviewer observed that taking written notes did interrupt the flow of conversation. Several participants expressed relief that the interview was not recorded. The interview questions helped the conversation transition into the storytelling that allowed the participants to share intimate details of their experiences with ME/CFS.

As would be expected, when participants shared their stories, they often mentioned the cities and states in which they lived. Further, many participants in describing their history with ME/CFS would name the clinics or doctors that treated them. In a few cases, some people were very specific with treatment regimens or pharmaceutical drugs they were using to treat different symptoms. In order to preserve anonymity of individuals, this type of information was omitted from the storyline. While participants were told before the interview that proper names of people and places would not be used, all final omissions were made after the interviewee shared their story as not to influence or interrupt the storytelling process. None of the participants requested including that type of information in their story.

Respecting the participant

The interview process itself maintained respect for the person with ME/CFS telling his or her story. The term respect is used in a broad sense to include recognition of the illness impact (i.e. symptom flare ups), scheduling (i.e. times and dates), and the personal nature of sharing intimate details. For example, in four cases, the scheduled interview time was cut short and rescheduled to finish at a future date. In another case, six interview

appointments were scheduled in advance in the effort to find a day in which illness symptoms could be managed. Of these six appointments, the actual interview took place on the 3rd date, allowing the patient to cancel the first two dates without causing added stress or inconvenience to the interviewer.

The interviewer, who has trained qualitative research expertise, also employed observational skills and active listening based on experiences with interviewing patients with ME/CFS. For example, the interview followed the pace of the interviewee without time pressures. As some people with ME/CFS have cognitive difficulties due to the illness, questions sometimes needed to be repeated or rephrased and this was done in a neutral manner. Finally, listening to the interviewee may mean going past the time limit or going outside the scope of the questions in order to make sure someone is being heard.

Story development

The interview guide (Table 1) served to start the interview process, and three participants asked to see the guide in advance of the interview. However, it quickly became apparent that in most cases the interviewer had no need to ask questions from the guide because proposed questions originated naturally as the story was being told. In essence, the guide served to ‘break the ice’ as the process of storytelling opened organically and deepened as participants shared their experiences. For example, as the person being interviewed starts to talk and the story unfolds, most questions from the guide were answered without being asked. Once the interview was completed, the interviewer reviewed notes and wrote the story based on qualitative methods, which incorporated being true to the words spoken by the person telling the story. Stories were developed by weaving verbatim quotes and phrases written down during the interview. The stories were directed by the patients and developed in the order that the patient told the story.

Once a story was complete, it was sent to the person for review and editing. Participants would further add, delete, and edit the story so it would be true to their voice and words. In some cases, the edits were minimal. However, in two instances participants provided several pages of feedback. When this occurred, the interviewer reached to the participants by telephone and email and explained the space limitations due to the website posting. Working as partners, the interviewer and participant reviewed the story together. In all cases the participant had final approval on all edits as well as the final product (including edits suggested during CDC clearance process).

Sharing the story

Upon completion and CDC clearance approval, each story was posted on CDC’s ME/CFS website. Stories were given a title and photo or image to accompany the story. As of December 2023, there have been 196,229 page views to the VOP section. The top three ways that people accessed the stories were through mobile devices, desktop, and tablets. The ME/CFS program has received anecdotal feedback on the series through emails sent to the CDC and by people reaching out to the program. In one instance, a person was so thankful that the series enabled family and friends to understand their experiences with ME/CFS that they volunteered to contribute to the VOP Project.

Discussion

Photovoice and hermeneutic phenomenology tenets guided the framework for interviews in which a participant is a partner with the interviewer to tell a personal experience narrative with ME/CFS. In photovoice the individual is a driving force in narration, and as such, the individual decides the perspective or starting point of sharing the experience. Similarly, hermeneutic phenomenology focuses on the lived experiences and personal aspects of a story [14]. As applied to VOP interviews, the focus on personal explanations and perspectives of living with ME/CFS, for example, of getting a diagnosis and the real-life experiences associated with ME/CFS. Importantly, capturing experiences by adhering to the word choices of the participant, empowers the participant and further enriches the story. The process enables diverse narratives and perspectives that also capture common elements of ME/CFS illness without preconceived ideas implemented by the interviewer or process.

We found that participation in this project enabled participants to be present in driving the interview process and make decisions about how the story is told. For example, participants partnered in all aspects: scheduling, revisions, and ensuring their story is shared using their voice, with the words and phrases spoken by the participant. Importantly the process built in flexibility to allow for the real-life symptoms that disrupt and affect individuals with ME/CFS.

The sharing of these stories has multiple purposes. Participants noted that it was important to share the story so family and friends could benefit from hearing other patients' stories to have a better understanding of what it is like to live with ME/CFS. For patients with ME/CFS, reading a story of someone who has the same illness may provide a sense of empathy and relief, and perhaps empowerment [11]. For example, one participant stated,

I learned to manage alone as best as I could, and over the years even became a master at hiding my illness from the outside world ... Although this illness continues to weigh heavily on my heart and body, having the knowledge I now have and knowing there's a growing community of support keeps me joyful and full of hope.

A spouse added, 'The biggest challenge for me was understanding what 'it' is. As an active person, it was tough for me to comprehend that chronic fatigue syndrome was more than just being 'tired'.'

Many patients with ME/CFS feel misunderstood by the healthcare system, and sharing these stories may benefit healthcare professionals by hearing from people with ME/CFS about how the illness has affected their quality of life in terms relationships, and daily life. One participant said,

Medical professionals need to see the disease from the patient's perspective. They need to understand what it is like to live with ME/CFS. They need to understand the burden of the disease itself and to end the stigma attached to it.

Another participant stated, 'It is just frustrating and exhausting that you have to do so much advocating for yourself because you do not have the capacity for it with this condition.'

VOP stories build a better picture that goes beyond the physical aspects of the illness. For example, many patients in the project told of having to visit a number of healthcare providers to either get a diagnosis or be heard in terms of their symptoms. Participants expressed the need for understanding what it is like to seek a diagnosis and how ‘grueling’ it is to see multiple healthcare providers just to find one who believes and listens to your story. For example, ‘Just getting a diagnosis for ME/CFS is very difficult and challenging,’ and a second person said, ‘The first thing I thought after getting my diagnosis was that someone believed me and “got it” without superfluous explanations.’ Another individual said,

I would tell healthcare providers that making a diagnosis is not difficult. A proper medical history is very important but it takes time. It is impossible to make a diagnosis in just 15 or 30 minutes. Most important is to look at the level of function before and after the illness began.

By telling these stories, patients with ME/CFS and their families hope that people find inspiration in the stories as well as become aware of ME/CFS and empathize with those who suffer with this debilitating illness.

The process outlined for the ME/CFS VOP project can be employed for other similar chronic or less-recognized illnesses. For example, given some similarities with ME/CFS to post COVID- 19 conditions or Long COVID, some people with Long COVID may benefit from telling their stories, using their own voice. Additionally, hearing the stories of people with Long COVID, told in patients’ own words, may help providers, caregivers, and the public better understand the experiences of these patients, their symptoms and the long-term effects of the condition.

While this project is of the qualitative nature, there are several limitations. First is the length of the story. We were limited to how much we could post on a website page and thus the stories are limited to a page and a half of text. We know in many cases patients would love to share more about the effects of the illness on their life story yet were limited to a predetermined page length. Second, in order to assure a level of anonymity to participants, we did not include names of clinics, universities, people or in some cases, certain medications. Last, while we continuously reached out to interviewees throughout the five-step process, we did not conduct an independent systematic evaluation with interviewees. However, we did hear unsolicited feedback from participants about how thankful they were to be given the opportunity to share their stories and participate in the project, with one person stating it was additionally therapeutic. CDC promoted VOP stories through sharing of Tweets, awareness day features, and website links. However, additional outreach for healthcare providers to read these stories would advance goals towards understanding what it is like to live with ME/CFS.

Conclusions

This project demonstrated the feasibility of incorporating tenets from qualitative methods in a systematic manner to interview people with ME/CFS, or caregivers, and enable them to share experiences in their own voice. We believe that by sharing these stories, the quality of care can be improved for ME/CFS patients as healthcare providers, the general public, and

researchers will have a better understanding of ME/CFS from the patient perspective. This project contributes to bringing the patient and caregiver perspective of living with ME/CFS to the public and highlights complexities involved with the illness.

The implications from this project are the application of tenets from photovoice and hermeneutic phenomenology to systematically guide the interviews and capture the voice of people with ME/CFS and caregivers. The five-step process replicates interviews across individuals but maintains the ability for participants to provide personal perspective and narration. The ME/CFS VOP story series allows patients with ME/CFS to share their individual personal experiences living with the illness. Participants are involved in the story development process from conception to posting and have full control over the perspective and story line.

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Table 1.

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) Voice of the Patient Interview Guide.

- . Prior to getting ME/CFS, did you know anything about it?
- . When did you start to feel ill? What was that like?
- . What symptoms did you have?
- . What are your health problems? How do they impact your life each day?
- . When did you start to think you should go to the doctor?
- . What happened after you went to the doctor?
- . What did the doctor tell you?
- . How long did it take for you to start feeling better?
- . How long did it take for you to learn to live with your illness?
- . What has been most helpful to you in learning to live with ME/CFS?
- . How do you feel today?
- . How has your life changed since being diagnosed with ME/CFS?
- . What would you like people to know about your experience?
- . How has ME/CFS impacted your family? Your friends?