“Power of Storytelling”: A Content Analysis of Chronic Pain Narratives on YouTube

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ABSTRACT

Background: First-person digital narratives are short videos produced independently by or in partnership with the person to tell their personal experience.

Objectives: The objective of this study was to describe how first-person digital narratives of adults with non-cancer pain are represented on YouTube. A secondary aim was to analyze first-person digital narratives hosted on pain management websites of professional organizations to explore whether these videos represented chronic pain with the same content.

Method: Guided by the methodological framework of Arksey and O’Malley, a conventional content analysis was undertaken analyzing the chronic pain videos published on YouTube and six global pain management websites.

Results: Of the 78 videos (54 YouTube and 24 pain websites) that were analyzed, the overarching theme “power of storytelling” suggests that personal stories were used as a medium to share lived experiences of chronic pain, providing help and advice to similar others. The four supporting themes were (1) My pain journey, (2) Navigating health care, (3) Pain and the impact on me, and (4) What works for me. There was no major difference in subthemes between the YouTube and pain website videos.

Conclusion: Digital narratives enable those living with chronic pain to voice their experiences and communicate their pain journeys and may thus provide a sense of validation. Digital narratives can be used as a therapeutic tool to provide insights for others into the lived experience of chronic pain and to provide peer support for people with pain. Future studies are needed to investigate the clinical effectiveness and implementation of digital stories in chronic pain management.

RÉSUMÉ

Contexte: Les récits numériques à la première personne sont de courtes vidéos produites de manière indépendante par la personne ou en partenariat avec elle pour raconter son expérience personnelle.

Objectifs: L’objectif de cette étude était de décrire comment les récits numériques à la première personne d’adultes souffrant de douleur non cancéreuse sont représentés sur YouTube. Un objectif secondaire était d’analyser les récits numériques à la première personne hébergés sur des sites Web de prise en charge de la douleur d’organisations professionnelles afin de déterminer si ces vidéos représentaient la douleur chronique avec le même contenu.

Méthode: À partir du cadre méthodologique d’Arksey et O’Malley, une analyse de contenu conventionnelle a été entreprise pour analyser des vidéos sur la douleur chronique publiées sur YouTube et sur six sites Web de prise en charge de la douleur.

Résultats: Sur les 78 vidéos (54 sur YouTube et 24 sur des sites Web sur la douleur) qui ont été analysées, le thème « le pouvoir du récit » porte à croire que les histoires personnelles ont été utilisées comme moyen de partager des expériences de douleur chronique vécues, en plus d’apporter de l’aide et de donner des conseils à d’autres personnes dans la même situation. Les quatre thèmes étaient (1) Mon parcours avec la douleur, (2) Naviguer au sein des soins de santé, (3) La douleur et son impact sur moi, et (4) Ce qui fonctionne pour moi. Il n’y avait pas de grande différence dans les sous-thèmes entre les vidéos diffusées sur YouTube et celles qui étaient diffusées sur des sites Web portant sur la douleur.

Conclusion: Les récits numériques permettent aux personnes vivant avec une douleur chronique d’exprimer leurs expériences et de communiquer leurs parcours avec la douleur, pouvant ainsi donner un sentiment de validation. Les récits numériques peuvent être utilisés comme un outil thérapeutique pour donner aux autres un aperçu de l’expérience de la douleur chronique et offrir du soutien par les pairs aux personnes souffrant de douleur. Des études futures sont nécessaires pour étudier la mise en œuvre et l’efficacité clinique des récits numériques dans la prise en charge de la douleur chronique.
Introduction

Chronic non-cancer pain in adults is a significant global health burden and is defined as pain that lasts or recurs for more than three months. Chronic non-cancer pain carries significant personal and economic costs, including work productivity loss, early retirement, and decreased quality of life. The causes of chronic pain are multifactorial and are frequently misunderstood by both health practitioners and the public. Furthermore, due to the often invisible nature of the condition, people living with chronic pain can be marginalized by society and clinicians and their realities minimized. This in turn leads to further psychological distress and poor health outcomes, including sleep disturbance, depression, and suicidal ideation.

Illness narratives are “. . . a story the patient tells, and significant others retell, to give coherence to the distinctive events and long-term course of suffering.” Illness narratives can help promote behavior change by increasing social skills, self-awareness and self-reflection. The activity of creating a narrative can also act as a healing process, promoting personal contemplation and emotional acceptance. An online field experiment that explored the impact of shared illness narratives on the working lives of 166 people with chronic inflammatory bowel disease found that personal relevance enabled the reader to connect with the storyteller, increasing motivation and perceived ability to work. These findings suggest that having platforms for people to communicate the experience of living with chronic pain may, in addition to providing a therapeutic intervention, improve public knowledge and awareness.

Social media is now established as a public media space where adolescents and adults living with chronic pain are connecting to share and access illness narratives. Previous studies have shown that members of online communities can benefit from mastery experiences of others, learning through vicarious experience to engage in self-management behaviors. Studies examining the portrayal of illness narratives of people living with chronic pain in social media platforms like Flickr, Tumblr, and Instagram have identified new visual and multimodal possibilities for pain communication. Another study analyzing social representations of chronic pain in four media sources (newspapers, Pinterest, YouTube, and the movie Cake) concluded that the type of medium shapes the message. The social media platforms (YouTube and Pinterest) provided first-person accounts, and the newspaper articles and the movie Cake, which was chosen as a case example for films, provided third-person accounts of pain. Social media platforms like YouTube facilitate wide dissemination of illness narratives by video, providing cost-effective ways of communicating chronic pain journeys, with wide-reaching impact, and thus the status and content of online pain narratives warrant further exploration.

A subset of illness narratives are first-person digital narratives: short videos produced independently by or in partnership with the person to tell their personal experience. These can be a combination of short video and audio clips complemented by images, animation, and music. First-person digital narratives enable self-validation of experience and allow sharing of self-management strategies, clinical advice, and peer support. As user-generated content, digital narratives may be of variable production quality depending on the source of content (e.g., videos from professional pain organizations). Further, the information may or may not align with recommended best clinical practices for people with chronic pain. Because first-person digital narratives may be a scalable mechanism for communicating the lived experiences of adults with chronic pain, we aimed to understand the representations of first-person digital narratives on YouTube. In addition, because health care providers commonly recommend professional pain management websites for self-management support, we wanted to explore the differences in representations of first-person digital narratives hosted on pain management websites and YouTube.

Methods

Because online video analysis is a nascent research field, we were guided by the scoping review methodological framework of Arksey and O’Malley and recommendations for searching and screening YouTube videos. The stages of the scoping review framework were adjusted for a scoping review of YouTube videos (1) to identify the research question; (2) to identify relevant videos; (3) to select videos; (4) to chart the data; and (5) to collate, summarize, and report the results. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension checklist for reporting scoping reviews was used to guide reporting of this study.

Identifying the Research Question

Two research questions were established before commencing the review: (1) How were lived experiences of adults with chronic pain represented in YouTube videos? (2) Were there differences between the representation of adults with non-cancer chronic pain video contents from pain management websites and YouTube?
**Video Selection/eligibility Criteria**

Videos were included if (1) the individual in the video was subjectively deemed by raters as aged 18 years or over; (2) the video primarily focused on the individual’s own experience or chronic pain story; (3) the video channel was a personal account, patient organization, professional pain organization, academic institution, or a hospital; (4) video duration greater than 1 min but less than or equal to 10 min based on the assumption that videos of shorter duration would be engaging and more likely to be used in clinical practice; and (5) the video was in English. Videos were excluded if (1) it was on cancer-related pain; (2) it focused on acute pain; (3) it was an advertisement and/or promotion of a medical or surgical procedure or a product; or (4) it primarily captured the health care professional’s perspective.

**Identifying Relevant Videos and Video Selection**

The YouTube search was completed on April 22, 2020, in New Zealand using Google search in Google Chrome. Pilot searches on YouTube through Google Chrome were undertaken to refine the search terms that produced the most relevant video content. Two members of the research team (ML and TE) conducted independent searches using two search terms: “chronic pain story” and “intitle:chronic pain story.” A new YouTube account was created and browser history was cleared to ensure that previous search history did not influence search results, a recommended strategy for YouTube reviews. Two members of the team (ML and TE) independently reviewed the title and metadata of videos for potential inclusion, in the order they were presented in the YouTube search list. Each video was then watched and the metadata were examined, both considered against inclusion criteria. Videos meeting inclusion criteria were added to a YouTube playlist (a function within YouTube to curate a collection of videos). ML and TE both created independent playlists based on the search terms. The screening of the search ceased when ten consecutive videos no longer met inclusion criteria, similar to a previous YouTube review.

A secondary search for video stories was conducted on global pain management websites that were identified in a previous review of pain management websites. One team member (KM) screened all sections of these 27 websites for eligible videos through link descriptions such as “Stories,” “Real Stories,” or “Patient Experiences.”

**Verification and Consensus**

Each video playlist of included videos was watched and screened independently by the other researcher to ensure that inclusion criteria had remained consistent between both reviewers. Discrepancies were noted. Mediation with a third member (DM) was then done to assess the inclusion of the videos with discrepant decisions. All three members, through discussion and re-watching of the videos, resolved disagreements regarding a video’s eligibility for inclusion.

**Charting the Data**

The final sample of included YouTube videos were divided between four members (DM, LT, ML, and TE) to extract descriptive characteristics. Metadata provided by YouTube were charted on a Microsoft Excel spreadsheet and the final data set was then checked by another member of the research team (HD). Data charted for each video included title of video, URL, name of YouTube channel, duration on YouTube (days), number of likes, number of dislikes, duration (minutes), number of views, number of comments, YouTube category (category assigned by creator based on video content; e.g., education, entertainment, comedy), video source (academic/medical research institution, health care company, educational organization, professional association, individual health care professional/academic, private account, news broadcaster, animation company, or other), video style (live action: talk to camera; role-play; lecture; interview, animation: whiteboard; 2D; 3D, still images, screencast, or combination; e.g., live action and still images), and country of origin.

**Collating, Summarizing, and Reporting the Results**

The video contents were analyzed using a conventional content analysis approach. To adapt this approach for video content, initially four of the included videos were randomly selected and watched by four members (DM, LT, ML, TE) independently to develop an initial content analysis framework. While watching each video, team members identified quotes that formed key concepts and then identified subthemes and themes relevant to the research question. Subsequently, a consensus meeting was held with all team members to finalize the initial coding framework by mutual consensus. The 78 videos were then split between two pairs of reviewers (DM and LT; ML and TE). Both members of each pair independently coded 39 videos by watching them multiple times and identified subthemes and themes relevant to the
coding framework, backed up with supporting quotes. A consensus meeting was held among each pair to compare coding and derive consensus by discussion. Then, all team members had a consensus meeting to derive the final themes and subthemes.

**Ethical Considerations**

Institutional ethics approval and informed consent were deemed not necessary because we collected information from publicly available videos, similar to previous YouTube evaluation reviews in chronic pain.\textsuperscript{11, 23} We have, however, adhered to the ethical principles recommended for Internet-mediated research by the British Psychological Society\textsuperscript{26} and we acknowledge that the issue of considering online information as public or private is a gray area, similar to previous Internet research by Toye et al.\textsuperscript{12} Although some transcribed quotes from the included videos were included as part of our content analysis, to ensure the anonymity of the analyzed videos, similar to Forgeron et al.,\textsuperscript{11} the quotes were searched verbatim in the Google database. This search did not retrieve the source video. Further, we have assigned numbers for the individual videos without providing original links to the videos to limit traceability.

**Results**

**Videos Included**

The YouTube search of title and metadata identified 66 videos (Figure 1), of which 12 were excluded, resulting in 54 videos. The videos were excluded because they were deemed advertisements for private health care providers ($n = 10$) and duplicates ($n = 2$). Secondary searching from six pain management websites (LivePlanBe, $n = 6$;
mypainfeelslike, \( n = 4 \); painHEALTH, \( n = 10 \); International Association for the Study of Pain, \( n = 2 \); and PainToolKit, \( n = 2 \) identified another 24 videos, resulting in 78 videos for final content analysis (Supplementary Tables 1 and 2).

**Characteristics of Included Videos**

Most of the included YouTube videos originated from the United States (45/54, 83%), with 28 videos posted by the U.S. Pain Foundation Inc. YouTube channel, marking the International pain awareness month in September 2019 (Supplementary Table 2). There were nine videos uploaded by individuals from private accounts and seven videos from private health care companies (Supplementary Table 2). The mean video duration was 4.93 min (range 1.01–9.54 min). Views ranged from 9 to 168,338, with a median of 290. Comments for videos ranged from 0 to 826, with a median of 4. The video with the most views and comments was “Fibromyalgia: Living with chronic pain—BBC stories” (Supplementary Table 2, video 1). YouTube categorized 33/54 of these videos to be educational, people and blogs (7/54) and science and technology (4/54). The videos had been posted between 79 and 2436 days before the date of search (Supplementary Table 2).

Most of the 24 videos found on the secondary search of pain management websites originated from three countries: Australia (\( n = 10 \)), Canada (\( n = 6 \)), and the UK (\( n = 5 \)). The mean video duration was 4.25 min (range 2.49–6.09 min). Views ranged from 176 to 55,091,815 with a median of 822. Comments for videos ranged from 0 to 33,803. The video with the most views and comments was “Never, Ever Give Up. Arthur’s Inspirational Transformation” (Supplementary Table 1, video 77). YouTube categorized 9/24 of these videos as people and blogs, educational (8/24) and science and technology (1/24). The videos from LivePlanBe were not located on YouTube, so the videos were not categorized and no information on comments was accessible (Supplementary Table 2).

**Video Content Analysis: Themes**

Our analysis found that “power of storytelling” was the overarching theme with four supporting themes: (1) My pain journey, (2) Navigating health care, (3) Pain and the impact on me, and (4) What works for me (Figure 2). The theme and subtheme descriptions with supporting quotes are presented in Table 1 and the frequency of subthemes is illustrated in Figure 3. There were no major differences in subthemes derived from the YouTube videos and pain management website videos (Table 2).

**Overarching Theme: Power of Storytelling**

The overarching theme of “power of storytelling” suggests that personal stories were used as a tool to share lived experiences of chronic pain, to provide help, advice, and support to similar others. The stories conveyed the journey of living with pain, challenges of navigating health care, the psychosocial impact of pain on the person, and the importance of finding pain management strategies that worked for them.

**My Pain Journey**

This theme encompassed personal experiences of chronic pain, including descriptions relating to the onset of pain (62/78, 79%), duration of symptoms (53/78, 68%), location of pain, and descriptions of their symptoms (e.g., severity and nature of pain; 64/78, 82%). Personal experiences from initial management of their symptoms via medications, exercises, and surgical interventions were also narrated (43/78, 55%; Table 1).

**Navigating Health Care**

This theme captured the challenges of navigating health care. Delays in receiving a diagnosis and both positive and challenging interactions with health professionals were portrayed. Delayed diagnosis covered how people described the often lengthy process before receiving a definitive diagnosis for the cause of their chronic pain (18/78, 23%). Stories of failed medical and surgical interventions that worsened symptoms or were ineffective and thus contributed to the chronicity of symptoms (19/78, 24%) and receiving inaccurate diagnoses from health care providers (23/78, 29%) were also shared (Table 1).

Examples of both positive (24/78, 31%) and negative health care professional experiences (29/78, 37%) were captured. People identified negative interactions such as feeling ignored or being mistreated by health care professionals in their search for a working treatment or answers for their pain. They reported a lack of compassion and understanding from health care professionals when they failed to receive individualized, person-centered care and felt disappointed when they were offered generalized and ineffective alternatives such as stand-alone pain medications. Positive interactions were narrated when they felt that they were listened to by health care providers who took an interest in wanting to help solve the complex problems associated with their chronic pain. Those professionals understood that the person was not just their pain and often took a holistic mind–body approach to pain management. People also
| Theme | Subthemes | Example 1 | Example 2 | Example 3 |
|-------|-----------|-----------|-----------|-----------|
| My pain journey | Pain onset (79%) | “... since 14 years old, I had knee surgery and then developed fibromyalgia” (Video 27) | “... a workplace shoulder injury 1997” (Video 60) | “... a Rugby injury five years ago” (Video 64) |
| | Acute, chronic, idiopathic, degenerative | “I spent years taking every sort of pill and narcotic” (Video 31) | “Over the years, I’ve tried different medications, none of which improved my situation” (Video 10) | “Doctors had prescribed me nine different medications for nerve pain, for muscle spasm, for some of the effects of the other meds” (Video 2) |
| | Initial management (55%) | “The pain was so bad I became physically ill, vomiting, and unable to get out of bed for three days” (Video 15) | “A combination of a burning pain and a nauseating ache ... shooting lightning pain into my legs” (Video 20) | “It feels like something is crushing down on my body, a terrible pressure that’s always there” (Video 61) |
| | Pain descriptions (82%) | “For the last 10 years I’ve been living with some pretty excruciating pain” (Video 55) | “I’ve lived with chronic headache pain for over 50 years” (Video 39) | “I’m now 33 years old, the accident happened when I was 13. And that’s been my life story” (Video 48) |
| | What their pain feels like | “My pain (79%)” | “They fused my spine from T9-L2, then L2-L3” (Video 13) | “I’ve had 20 surgeries in 10 years” (Video 25) |
| | Intensity (mild, moderate, severe) | | “Some [doctors] don’t even know about it, that’s why it took me so long to get diagnosed, because I’m from a small town” (Video 43) | “They’ve never been able to find a diagnosis” (Video 42) |
| | Location and symptom characteristics | | “Arthritis, spinal stenosis, degenerative disk disease ... and I began to buy into it” (Video 5) | |
| | Pain duration (68%) | | “I noticed that health care practitioners lacked the empathy and compassion I would expect for myself [a nurse]” (Video 12) | |
| | How long they have had chronic pain | | “I was finally able to have someone to communicate with, like, who actually understood my pain” (Video 7) | |
| Navigating health care | Surgical intervention (24%) | “The surgeries may have stabilised my back but have done nothing for the pain” (Video 30) | “I was born with all these conditions but spent a lifetime in pain because these were misdiagnosed or mismanaged or observed properly” (Video 61) | “The medical people told me the pain was all in my head” (Video 60) |
| | Unnecessary, ineffective, worsening symptoms. | | “I noticed that health care practitioners lacked the empathy and compassion I would expect for myself [a nurse]” (Video 12) | |
| | Time to get diagnosed (23%) | “It took a year of tests and doctors for them to figure out what was wrong with me” (Video 29) | “I was finally able to have someone to communicate with, like, who actually understood my pain” (Video 7) | |
| | How long from onset of pain until diagnosis? | | | |
| Misdiagnosed (29%) | Misdiagnosed before receiving definitive diagnosis by health care providers | “I was misdiagnosed with various things for almost 30 years” (Video 8) | “Arthritis, spinal stenosis, degenerative disk disease ... and I began to buy into it” (Video 5) | “I was born with all these conditions but spent a lifetime in pain because these were misdiagnosed or mismanaged or observed properly” (Video 61) |
| | Negative interactions (37%) | “You just have chronic back pain and there’s nothing we can do for you” (Video 2) | “I noticed that health care practitioners lacked the empathy and compassion I would expect for myself [a nurse]” (Video 12) | “The medical people told me the pain was all in my head” (Video 60) |
| | Mistrust, being shunned, not believed, lack of compassion/understanding, or other negative experiences | | “I was finally able to have someone to communicate with, like, who actually understood my pain” (Video 7) | |
| Positive interactions (31%) | Being listened to, taking the time to explain, new treatments, pain mechanisms, holistic approach, or other positive experiences | “Not only to have someone finally validate it and sit down in front of you and tell you what you have has a name and we can treat it, but also that it exists” (Video 4) | “I was finally able to have someone to communicate with, like, who actually understood my pain” (Video 7) | “They were extremely kind and nice, reassured me it wasn’t in my head ... [they were] thorough and kind and listened to my previous experiences” (Video 43) |
| Pain and the impact on me | Psychological (77%) | “Like it’s something you’ve created, like you’re mad, years feeling like you are cuckoo” (Video 1) | “Chronic pain does not come by itself, it brings with it rage, anxiety, loneliness and helplessness. This is why I became suicidal” (Video 6) | “I got to the point where I was just so depressed and in so much pain and it seemed like no one could help me” (Video 11) |
| | The negative impact of pain on mental health leading to anxiety, depression and frustration | | “I went from being independent, smart, active to being stuck in bed” (Video 25) | “He spent a lot of time literally carrying me up and down stairs” (Video 1) |
| | Activities of daily living (64%) | “I could no longer care for my kids, cook for my family” (Video 20) | “I lost hours of everyday having to lay down on my back” (Video 2) | “I wasn’t able to look at the computer screen or type. I had to walk away because I was in so much pain” (Video 15) |
| | Loss of function, sleep deprivation, and reliance on others | “Financial anxiety became a big factor” (Video 6) | “To hear people dismiss it so lightly made me feel further alone” (Video 6) | “You become socially isolated by your pain because people don’t want to see you suffer like that” (Video 13) |
| | Work (53%) | | | |
| | Inability to work effectively, losing job, financial burden. | | | |
| | Relationships (71%) | “I don’t like it when it robs me from being the mum that I wanted to be to my children” (Video 1) | | |
| | Social isolation and strained relationships with family and friends, lost hobbies/sports and school | | | |
Table 1. (Continued).

| Theme | Subthemes | Example 1                                                                 | Example 2                                                                 | Example 3                                                                 |
|-------|-----------|---------------------------------------------------------------------------|---------------------------------------------------------------------------|----------------------------------------------------------------------------|
| What works for me | Pain education (19%) | "I learned that it hurts but there's no damage" (Video 55) | "Learning about the neuroscience and how I could process my pain could actually make it better" (Video 1) | "In this course that I did it showed that you've got pain and you've got to accept it. But don't give it the domination and you can keep on living" (Video 65) |
|       | Learning about how pain works to reduce catastrophizing thoughts | (Video 39) | (Video 61) | (Video 67) | (Video 23) | (Video 24) |
|       | Activity pacing (17%) | "Don't try to do everything all at once ... try spacing and pacing your activities out" (Video 9) | "I pace my activity; when I do things I do it step by step" (Video 9) | "I make the most of my good days and know when I need to rest" (Video 23) | (Video 23) | (Video 24) |
|       | Completing activities in increments interspersed with periods of rest | (Video 1) | (Video 1) | (Video 23) | (Video 24) | (Video 24) |
|       | Thought and behavioral management (58%) | "I understand that pain is inevitable but suffering is optional" (Video 9) | (Video 23) | (Video 24) | (Video 24) | (Video 24) |
|       | Acceptance of pain, cognitive behavioral therapy | (Video 60) | (Video 56) | (Video 6) | (Video 56) | (Video 6) |
|       | Exercises (32%) | "I truly believe that if I don't stay active it's just going to get worse" | "I spend three hours in the water. ... Finally, I started to feel like I could start living was when I started going to the pool" (Video 60) | (Video 56) | (Video 1) | (Video 1) |
|       | Biomechanical exercise aimed at limiting pain from the source (e.g., Pilates, McKenize exercises) | (Video 23) | (Video 24) | (Video 24) | (Video 24) | (Video 24) |
|       | Aerobic exercise aimed at improving overall cardiovascular health (e.g., walking, swimming) | (Video 60) | (Video 56) | (Video 6) | (Video 56) | (Video 6) |
|       | Relaxation/breathing (10%) Self-calming methods | "I have found that deep breathing reduces my pain level somewhat" (Video 39) | "Gentle yoga has been great" (Video 42) | "With the breathing and the meditation, the different steps I've taken in the last 18 months has been phenomenal" (Video 65) | (Video 65) | (Video 65) |
|       | Meditation/mindfulness (22%) | "It has completely transformed the way that I respond to my pain and the way that I interpret it" (Video 1) | "What's been most beneficial in the long term has been meditation, reading, journaling" (Video 58) | "And mindfulness has helped reduce my pain and gives me a sense of peace" (Video 39) | (Video 39) | (Video 39) |
|       | Interventions targeted at viewing the body as a whole—incorporating mental, physical, spiritual, psychological aspects of health | (Video 1) | (Video 58) | (Video 58) | (Video 58) | (Video 58) |
|       | Distraction techniques (15%) | "When you're living with chronic pain, you're looking for ways to fill your life with low level happiness" (Video 9) | "Even if you're bringing yourself away from the pain for 10 minutes, you're doing something positive" (Video 55) | "Marijuana doesn't take my pain away, but it takes my mind off it" (Video 30) | (Video 30) | (Video 30) |
|       | Taking the focus away from your pain | (Video 9) | (Video 55) | (Video 58) | (Video 58) | (Video 58) |
| Problem solving (49%) | Adapting coping strategies when faced with flare-ups and relapses of pain | "They [pain educators] give us the tools for coping with that" (Video 5) | "I would play angry music on purpose with the intent to get me on the right sort of energy" (Video 58) | "I take drugs at night to help me sleep and ease the pain, and I use heating pads for the pain and a breathing App to kind of control and reduce pain" (Video 29) | (Video 29) | (Video 29) |
|       | | (Video 5) | (Video 58) | (Video 29) | (Video 29) | (Video 29) |
| Goal setting (9%) | Developing goals in order to achieve a desired outcome in the patient's life | "In order to keep being able to travel I need to stay physically active and ready to go" (Video 44) | "I had this goal of running a half marathon" (Video 2) | "I found if I didn't have a goal I wouldn't be motivated to do anything. Goals to get better are really good" (Video 71) | (Video 71) | (Video 71) |
|       | | (Video 44) | (Video 2) | (Video 71) | (Video 71) | (Video 71) |
|       | Condition support groups (40%) Online or community groups for pain expression and peer support | "We stand up for each other and we look out for each other" (Video 19) | "I'm involved with advocacy so that people don't have to go through the same things I did and to wait so long for a diagnosis" (Video 21) | "I believe getting new friends who are going through the same things as you is a real booster ... it helps you get through the day because you know that it's not just you that's dealing with this" (Video 56) | (Video 56) | (Video 56) |
|       | | (Video 19) | (Video 21) | (Video 56) | (Video 56) | (Video 56) |
| Advice to others (83%) | Providing the viewer with advice and advice for similar others in their pain journey | "This message of hope—it's possible to get your life back and do things that you want to. I want to let you know that it's going to be okay" (Video 17) | "Keep a journal to help the doctors figure things out" (Video 18) | "Listen carefully to what the doctors are trying to explain and then explain back to them how they can help me" (Video 21) | (Video 21) | (Video 21) |
emphasized that these health professionals were refreshingly honest in saying what they can and cannot do, which took the burden of uncertainty off them (Table 1).

### Table 2. Comparison of the relative frequency of subthemes between the YouTube and pain management website videos.

| Themes and subthemes                          | YouTube videos (N = 54) (%) | Pain website videos (N = 24) (%) | Difference (%) |
|-----------------------------------------------|-------------------------------|----------------------------------|----------------|
| My pain journey                               |                               |                                  |                |
| Pain onset                                    | 74 (40/54)                    | 92 (22/24)                       | 18             |
| Initial management                            | 52 (28/54)                    | 63 (15/24)                       | 11             |
| Pain description                              | 85 (46/54)                    | 75 (18/24)                       | 10             |
| Duration of pain                              | 67 (36/54)                    | 71 (17/24)                       | 4              |
| Navigating health care                        |                               |                                  |                |
| Ineffective surgical interventions            | 22 (12/54)                    | 29 (7/24)                        | 7              |
| Delay in diagnosis                            | 26 (14/54)                    | 17 (4/24)                        | 9              |
| Misdiagnosis                                  | 37 (20/54)                    | 13 (3/24)                        | 24             |
| Negative interactions with health care providers | 37 (20/54)                    | 38 (9/24)                        | 1              |
| Positive interactions with health care providers | 31 (17/54)                    | 29 (7/24)                        | 2              |
| Pain and the impact on me                    | 70 (38/54)                    | 92 (22/24)                       | 22             |
| Negative psychological effect                 | 67 (36/54)                    | 50 (12/24)                       | 17             |
| Negative impact on daily activities           | 44 (24/54)                    | 71 (17/24)                       | 27             |
| Negative effect on relationships              | 67 (36/54)                    | 79 (19/24)                       | 12             |
| What works for me?                           |                               |                                  |                |
| Pain education                                | 16 (9/54)                     | 25 (6/24)                        | 9              |
| Activity pacing                               | 15 (8/54)                     | 21 (5/24)                        | 6              |
| Thought and behavioral management             | 50 (27/54)                    | 75 (18/24)                       | 25             |
| Exercises to limit pain                       | 24 (13/54)                    | 50 (12/24)                       | 26             |
| Relaxation/breathing                          | 5.5 (3/54)                    | 21 (5/24)                        | 15.5           |
| Meditation/mindfulness                        | 13 (7/54)                     | 42 (10/24)                       | 29             |
| Distraction techniques                         | 5.5 (3/54)                    | 38 (9/24)                        | 32.5           |
| Problem solving to cope with pain             | 39 (21/54)                    | 71 (17/24)                       | 32             |
| Goals for pain management                     | 9.3 (5/54)                    | 8.3 (2/24)                       | 1              |
| Involved in support groups                    | 46 (25/54)                    | 25 (6/24)                        | 21             |
| Giving advice to others                       | 78 (43/54)                    | 92 (22/24)                       | 14             |

### Pain and the Impact on Me

This theme captured how people describe the complex impact of chronic pain on their lives. Psychological impacts covered how people often described the cognitive and emotional burden of chronic pain, expressed in the form of dealing with depression, frustration, and anxiety (60/78, 77%). Participants expressed the impact of pain on activities of daily living and discussed how basic functional movements were made too difficult or painful to complete leading to a loss of independence (50/78, 64%). People shared stories of lost jobs or having to stop working due to their pain, leading to financial complications and distress (41/78, 53%). People also frequently discussed the social impact of living with chronic pain in the form of difficulty maintaining healthy relationships with friends and family and the social isolation and strain that resulted in (55/78, 71%; Table 1).

### What Works for Me

This theme captured the beneficial skills and strategies adopted by people living with chronic pain. People described building self-efficacy through skill utilization such as learning about pain physiology (15/78, 19%), activity pacing (13/78, 17%), becoming accepting of their pain via thought and behavior management (45/78, 58%), benefits of exercise (25/78, 32%), relaxation/breathing control (8/78, 10%), meditation and mindfulness (17/78, 22%), distraction techniques (12/78, 15%), and goal setting (7/78, 9%). Problem-solving and adapting coping strategies when faced with flare-ups (38/78, 49%) were also discussed. Many participants provided this information in form of advice to the viewers (65/78, 83%). Finally, this theme also recognized the benefits of joining community groups (31/78, 40%) and forming

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**Figure 2.** Overview of overarching theme, supporting theme, and subthemes.
relationships with similar others as a way of advocating and validating their condition (Table 1).

**Comparison of YouTube and Pain Management Website Videos**

There was no major difference in the frequency of subthemes between YouTube and pain website videos (Table 2). For the theme “what works for me” there was a more frequent occurrence of subthemes focusing on self-management strategies in videos hosted in pain management websites compared to YouTube (Table 2).

**Discussion**

The primary purpose of this study was to explore how lived experiences of chronic pain are represented online as a way of understanding first-person digital narratives. The overarching theme of the “power of storytelling” suggests that personal digital stories were used as a tool to share lived experiences of chronic pain, often with the intent to provide help, advice, and support to similar others. The stories conveyed the journey of living with pain, challenges of navigating health care, and psychosocial impact on the person and their social relationships. People living with chronic pain described their journey through discovering successful self-management strategies that worked for them and emphasized the importance of finding support services.

Our results suggest that sharing personal pain stories via short videos may be an accessible and engaging tool to improve self-efficacy through vicarious experiences of listening to similar others. Pain self-efficacy is the confidence in one’s ability to engage in valued activities despite pain and is one of the key outcomes to predict long-term positive functional outcomes in people living with pain. Self-efficacy can be fostered via mastery experience, vicarious experience, verbal persuasion, and psychological factors (e.g., emotions and beliefs). The social ecological theory acknowledges the influence of the social environment on health behavior and may be a relevant theory for understanding these pain experience narratives. It is plausible that if positive experiences of pain self-management strategies are shared through a community-based platform (YouTube), people with chronic pain may be more inclined to try the shared strategies and thus reinforce their ongoing self-management. However, the influence of such digital stories on improving self-efficacy and fostering health behaviors requires further research.

These results suggest YouTube as a viable platform that provides people living with chronic pain the ability to share their stories and the opportunity to communicate their lived experiences as a way of social validation to their often invisible condition. Through these videos, people were able to explain their pain and articulate descriptive characteristics unique to their condition. The previous synthesis of qualitative studies aiming to explore patient experiences of chronic nonmalignant
musculoskeletal pain have alluded to the difficulty for patients to construct an explanation for their suffering and the struggle to explain the pain that does not fit an objective biomedical category. Thus, the dissemination of digital stories through social media platforms like YouTube has the potential to be an effective tool for pain communication. The process of creating digital stories and giving individuals the opportunity to describe their own experience in this form has been shown to produce positive feelings and a sense of control for the storyteller and their health. The process of sharing, constructing, and listening to similar others through stories elicits feelings of empowerment and empathy and strengthens social connection.

People shared their experiences of navigating the health care system and how interactions with health care professionals impacted their pain journey. Similar to the findings from a recent evaluation of news media stories representing chronic pain in New Zealand, people mainly shared challenging experiences in navigating the health care system. These were related to expressing the impact of failed pharmacological and surgical treatments, which highlights the consequences of “low-value” care where harms outweigh the benefits. A global call for health professionals has been made to reduce “low-value” care and adopt an active self-management approach through nonpharmacological treatments (e.g., education, exercise, and cognitive treatments) as a primary intervention for chronic pain management. This approach also acknowledges the need to address misconceptions about the causes, prognosis, and effectiveness of different treatments in the population and among health care providers. Our findings in this medium suggest that these recommendations are not being met, because narrators reported that nonpharmacological treatments were only offered after failed pharmacological and surgical treatments.

Our findings of digital stories used as a medium for pain self-expression and voicing of multifaceted burden concur with previous studies evaluating the portrayal of chronic pain in social media and news media. The holistic burden placed on individuals suffering from chronic pain affects all aspects of their lives, not just the physical. People frequently referred to the psychoemotional, social, and psychological impacts of living with ongoing pain, making them increasingly difficult to express and validate to others, including health care professionals. Creating digital narratives provides an audio-visual representation of such holistic burdens and lets an individual express them in a way that resonates with their experience.

We identified an expression of a perceived lack of compassion and understanding about holistic burdens from health care professionals in clinical encounters. The benefits of having mutual respect and a therapeutic alliance between health care providers and patients with chronic pain are well reported. The complexities of the therapeutic alliance between patients with chronic pain and health care providers were explored in a metasynthesis. This qualitative systematic review examined the perceived enablers and barriers to ongoing self-management that health care providers can foster through nonjudgmental communication, empathetic listening, and adopting holistic person-centered care. By contrast, poor patient–clinician relationships were reported when the person felt ignored or not listened to or believed and received conflicting information from health care professionals. This reinforces that people with chronic pain need to be heard and acknowledged by the health care professionals whom they are seeking validation from. Health care professionals have the opportunity to use these digital narratives to gain deeper insights, build relationships centered on respect and understanding, promote therapeutic alliance, and foster self-management.

Although YouTube is a popular platform for sharing videos, there are several caveats when searching for health information and patients’ stories. Firstly, because it is a public domain, anyone can disseminate health information and there is no monitoring of the video content accuracy unless it breaches the platform’s code of conduct. This can lead to inaccurate health misinformation being easily shared. Another observation from our review was the pervasive presence of advertising on YouTube, an open-source, commercial platform. Many videos found in the initial searches were produced by for-profit health care companies and may therefore contain information to support their commercial interests. For example, many videos that were excluded from our review had titles suggesting that they were simply a patient sharing their story; however, those videos were edited advertisements promoting books and commercial surgical devices. Despite these caveats, the increased presence of professional pain advocacy groups (e.g., International Association for the Study of Pain) and patient-led initiatives (e.g., Pain Toolkit) providing global pain education and offering comprehensive playlists to educate self-management support is promising.

Our review findings have insights for future research. As video stories is an emerging area in chronic pain research, future studies focusing on understanding patient perspectives of accessing and making sense of video stories may provide deeper perspectives of these online health resources in fostering pain self-management support. Another recommendation for ethnographic studies capturing the experiences of
patient-produced videos with pain clinicians could gain insights on an empathetic understanding of pain clinicians. Future research should also capture video stories of people with chronic pain from non-Western countries, because most of the included videos were from the United States, Australia, Canada, and the UK.

**Strengths and Limitations**

Although we followed the recommendations in conducting reviews on YouTube,²¹ we acknowledge the following methodological limitations. Firstly, the patient stories in the videos examined were not necessarily generated for the primary purpose of describing one’s illness narrative. Future studies specifically eliciting one’s illness narrative could provide deeper insights into living with chronic pain. Next, videos were included if they were English and less than 10 min in duration. Though the majority of existing videos fit these criteria, we were unsure how the excluded videos could have impacted our study findings. Secondly, due to our specific inclusion criteria, our search results may not have mimicked an average user’s search strategy. The key search term “intitle: chronic pain story” is highly specific and presented 28% more eligible videos than the search term “chronic pain story.” Though including this term strengthened the evaluation, it is unlikely that someone would have used this technique to find videos. People are likely to search regarding their condition (e.g., back pain, fibromyalgia), so future research could consider condition-specific terms. Most people from the included videos indicated not yet having a definitive diagnosis, so utilizing the umbrella term of “chronic pain story” includes those at all stages of their pain journey. Thirdly, YouTube employs a title-based search strategy. Though this is useful for specific video searches, YouTube cannot analyze video content in the way a Google search would for text-based resources. Therefore, our search would have missed videos on chronic pain that did not have the term explicitly in the title. This became evident when “Never, Ever Give Up. Arthur’s Inspirational Transformation,”¹⁴⁰ sourced from the Pain Toolkit website, had 55 million views yet was not discovered in the primary YouTube search. Lastly, videos were selected as they presented from most to least relevant. This aided the reproducibility of the search but may have narrowed the number of videos found compared to finding videos through the snowball effect.

**Clinical Implications**

Our study has several clinical implications. Firstly, digital stories are not only beneficial to the curator but may also act as a useful therapeutic tool for educating others. The videos often consisted of helpful self-management strategies and advice to others. Current and future health professionals could use these videos to enhance empathy by understanding people’s frustration and the significance of living with chronic pain. Clinically, this also presents an opportunity to incorporate tailored videos as a cost-effective adjunct to face-to-face treatment.²⁴ Reinforcing self-management strategies through vicarious experience may further support someone with chronic pain. Secondly, YouTube videos provide holistic information focused on navigating health care, whereas videos from pain management websites tended to refer to specific self-management strategies. Clinicians need to be cognizant of this difference when referring patients to these resources. From a health literacy perspective, most pain websites curated written resources to complement videos, thus providing learners with multimodal educational opportunities. Both YouTube and pain websites are accessible and engaging, but some may perceive pain management websites as a more reliable source of information.²⁴ Lastly, the sense of catharsis and community when participating in digital storytelling as part of a group-based pain management program was alluded to in our findings. Being acknowledged by a wider, more culturally diverse group of people going through similar situations acts to empower the individual and could be integrated into routine pain management programmes.

**Conclusions**

Through the power of storytelling, first-person digital stories take viewers on an individual’s journey through the struggles and challenges faced by people living with chronic pain. YouTube and pain management websites provide a public platform to vocalize people’s pain journeys, highlight the struggles of navigating health care, and discuss the holistic burdens that chronic pain creates. This medium can be utilized as an educational tool for the public, people living with pain, and health care providers to gain access to the lived experiences of people living with chronic pain. Future studies are needed to investigate the effectiveness and impact of digital stories to improve clinical outcomes in people with pain and the potential for integrating digital stories in clinical practice by health care providers.

**Acknowledgments**

We thank Michael Fauchelle, liaison librarian from the University of Otago, Wellington, New Zealand, for assisting with our initial search strategy.

**Disclosure Statement**

Hemakumar Devan has not declared any conflicts of interest. Toa Elphick-laveta has not declared any conflicts of interest.
Maxwell Lynch has not declared any conflicts of interest. Katie MacDonell has not declared any conflicts of interest. David Marshall has not declared any conflicts of interest. Leah Tuhi has not declared any conflicts of interest. Rebecca Grainger has not declared any conflicts of interest.

**Funding**

This research was funded by the School of Physiotherapy, University of Otago, New Zealand (2020).

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**Data Availability Statement**

All raw data on coding are available from the corresponding author up on request.

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