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OPEN

Understanding Pancreatic Diseases Using Animated Pancreas Patient

Informing Patients for Better Health Outcomes With Visual Formats of Learning

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Objectives: The aim of this study was to evaluate the impact of *Animated Pancreas Patient* (APP) educational modules (APP website and YouTube) on pancreas education, awareness, and health outcomes.

Methods: This was a retrospective study of APP metrics data from September 2013 to October 2017. We evaluated audience reach (number of visit sessions, unique visitors, page views) and calculated top views by media type (animation, expert video, patient video, and slide show) and top retention videos from the modules. We also assessed the educational impact through learner feedback survey.

Results: The APP had 1,475,252 views (547,693 unique visitors, 63.1% in United States) during the study period. Most popular topic viewed among the animations was "Role and Anatomy of the Pancreas" (n = 361,116), and most common expert video viewed was "Chronic Pancreatitis: What Foods and Beverages Should I Avoid?" (n = 31,667). Participants who completed the online feedback survey reported knowledge gains and commitments to change.

Conclusions: Pancreas education in visual formats of learning provided by APP demonstrated wide reach and has substantial potential to inform and impact behaviors of patients and caregivers. Continued efforts should be made to provide patient resources that address health literacy and patient education and respond to patient needs for better quality of life and improved health outcomes in pancreatic diseases.

Key Words: health literacy, health outcomes, pancreatic diseases, patient education, visual formats of learning

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Pancreatic diseases cause substantial morbidity, mortality, and costs. Pancreatic ductal adenocarcinoma is the fourth leading

cause of cancer mortality in the United States with an estimated 55,440 new diagnoses and 44,330 deaths in 2018.¹ Pancreatic ductal adenocarcinoma is also a leading cause of mortality among all cancers of the digestive system² and is estimated to become the second leading cause of cancer-related death in the United States by 2020.³

Acute pancreatitis (AP) is one of the most frequent gastrointestinal causes of hospital admissions in the United States. In 2012, AP accounted for 330,561 emergency department visits and 239,839 subsequent hospitalizations from emergency department visits.² Chronic pancreatitis (CP) is characterized by chronic abdominal pain, frequent exacerbations, and exocrine/endocrine insufficiency.⁴ Incidence of CP is quantitatively lower compared with AP, but significantly affects patients' quality of life.⁵

The economic burden from pancreatic diseases is increasing over the past several years in the United States. Recent estimates from 2014 hospital inpatient data showed AP, CP, and pancreatic ductal adenocarcinoma accounted for \$2.6 billion, \$134 million, and \$688 million in aggregate costs, respectively.⁶

Understanding mechanisms of early events in disease development and new approaches for early detection is necessary for better outcomes.⁷ One of the key factors that can negatively impact patients' health outcomes is low health literacy.^{8–11,12} Prior studies have linked lower levels of health literacy to poorer health-related quality of life¹³ and a lower likelihood of receiving chemotherapy (cancer patients).¹⁴ Although there are several reports on increasing burden of pancreatic diseases, data on patient education on quality of life and health outcomes are limited.

In this study, we evaluated National Pancreas Foundation's (NPF's) *Animated Pancreas Patient* (APP) as a patient education resource based on visual formats of learning, to help address patient gaps in understanding, reduce learning barriers in order for

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FIGURE 1. Animated Pancreas Patient website.

patients to make informed decisions, improve behaviors, and better partner with their health providers to attain optimal health outcomes, for over a period of 4 years.

<p>Animations</p> <p>Module: Understanding Pancreatitis (4 animations) Module: Management of Pancreatitis (2 animations) Module: Pancreatic Cancer (4 animations) Module: Endoscopic Procedures (2 animations) Module: Pancreatic Surgery (1 animation) Module: Nutrition and PERT (1 animation)</p>	<p>Expert Videos</p> <p>Module: Understanding Pancreatitis (12 videos) Module: Management of Pancreatitis (12 videos) Module: Pancreatic Cancer (25 videos) Module: Endoscopic Procedures (13 videos) Module: Nutrition and PERT (3 videos) Module: Pancreatitis in Kids and Teens (24 videos)</p>
<p>Patient Slide Shows</p> <p>Module: Understanding Pancreatitis (4 slide shows) Module: Management of Pancreatitis (2 slide shows) Module: Pancreatic Cancer (4 slide shows) Module: Endoscopic Procedures (2 slide shows) Module: Pancreatic Surgery (1 slide show) Module: Nutrition and PERT (2 slide shows)</p>	<p>Patient Experience Videos</p> <p>Module: Understanding Pancreatitis (10 videos) Module: Management of Pancreatitis (7 videos) Module: Nutrition and PERT (2 videos)</p>

FIGURE 2. Overview educational content available on Animated Pancreas Patient. PERT indicates pancreatic enzyme replacement therapy.

MATERIALS AND METHODS

Study Design and Participants

This is a retrospective review of APP website and YouTube audience data from September 2013 through October 2017. The NPF launched the initial English version of the APP website in September 2013; we therefore included all data from September 2013 through the latest measureable month (October 2017). Participants visiting the APP website and YouTube channel comprised patients and their family/caregivers and health care professionals involved and/or interested in the care of patients with pancreatic diseases.

Content Development and Access

A multidisciplinary faculty was selected from NPF's scientific advisors of gastroenterologists and endoscopists, pancreatic surgeons, pediatric gastroenterologists, nutritionists, and medical and surgical oncologists to provide expert guidance and approval of content for the APP website (Fig. 1). The task of the faculty included review of the evidence-based medical literature, approval of all content and feedback on learner activities, and the review of content for sensitivity to level of health literacy. The text, voiceovers, and images are crafted to serve a lay audience with a grade 6 to 8 literacy level (as tested with online tools). Each module is created to be succinct, practical, informative, evidence based, and aligned with the chosen learning objectives (Fig. 2).

Content

The APP content developed by the scientific advisors contains 14 animations, 86 expert videos, and 17 patient experience videos. Each of these videos is 3 to 4 minutes long. The APP education modules can be accessed directly from NPF's websites^{15,16} (<https://pancreasfoundation.org>, <http://www.animatedpancreaspatient.com>) or through the APP YouTube channel (<https://www.youtube.com/user/ThePancreasPatient>).¹⁷ The APP website and YouTube channel education modules are publicized by NPF chapters and through NPF outreach at national conferences. The APP website homepage also prompts users to provide feedback on user identity (patient, family/caregiver, health care provider, other), impact of the provided content on future actions and commitment to change, and evaluation of the quality of the educational material. The list of available animations, expert videos, and patient experience videos is illustrated in Supplementary Table 1, <http://links.lww.com/MPA/A686>. The optional feedback survey questionnaire is illustrated in Supplementary Table 2, <http://links.lww.com/MPA/A686>.

User Metrics Measurement and Statistical Analysis

Data were reported as frequencies and proportion and mean (standard deviation) where appropriate. We evaluated audience reach, demographics, and metrics such as number of visit sessions, number of unique visitors, page views, duration of page views, and duration of video views for the APP website and the APP YouTube channel. We also calculated top views, top views by media type (animation, expert video, patient experience video, slide show), and top retention videos overall for the APP website and YouTube channel. Finally, we assessed the educational impact of the APP program from the feedback survey data.

RESULTS

Participant Characteristics

Between September 6, 2013, and October 5, 2017, the APP website and YouTube channel had 1,475,252 total views (APP = 274,906; YouTube = 1,200,346) and 547,693 total unique visitors (APP = 67,553; YouTube = 480,140). Overall, the educational

content was accessed by participants from 159 countries, with a total of 3,054,490 minutes watched on YouTube. Most of the unique visitors (63.1%) to the APP website were from the United States, and 36.9% were from other countries.

A total of 4869 participants took part in the feedback survey. More than half of participants (54.6%) identified as patients; the rest were family caregivers (16.9%), health care providers (13.9%), and other (14.6%). The survey participants indicated they had learned about the APP website via their doctor (6.5%), nurse/pharmacist (0.3%), family/friend (2.2%), internet search (84.2%), or other (6.8%).

Popular Topics for the Animation, Expert Videos, and Patient Videos

Table 1 lists the most popular topics for the animation and videos. "Role and Anatomy of the Pancreas" (361,115 views), "Chronic Pancreatitis" (289,923 views), "Acute Pancreatitis" (157,076 views), "Understanding ERCP" (114,472 views), and

TABLE 1. Top 10 Animations, Expert Videos, and Patient Experience Videos by Frequency

Video Type	Video Title	YouTube	APP	Total
Animations	The Role and Anatomy of the Pancreas	351,181	9934	361,115
	Chronic Pancreatitis	282,710	7213	289,923
	Acute Pancreatitis	136,910	20,166	157,076
	Understanding ERCP (endoscopic retrograde cholangiopancreatography)	105,251	9221	114,472
	Pancreatic Surgery: Benefits, Risks, and Relevant Anatomy	56,129	1848	57,977
	Understanding EUS-FNA (endoscopic ultrasound with fine-needle aspiration)	45,419	3871	49,290
	Management and Treatment of Acute Pancreatitis	18,992	3496	22,488
	Management and Treatment of Chronic Pancreatitis	8256	8363	16,619
	Pancreatic Cancer: Treatment and Outcomes	12,060	3840	15,900
	Pancreatic Cancer: Signs, Symptoms, and Risk Factors	9844	4906	14,750
Expert videos	Chronic Pancreatitis: What Foods and Beverages Should I Avoid?	30,153	1514	31,667
	How Can You Keep the Pancreas Healthy?	11,779	1335	13,114
	How Is Acute Pancreatitis Treated?	7912	535	8447
	What Are the Different Stages of Pancreatic Cancer?	5174	322	5496
	What Is the Link Between Alcohol and Acute Pancreatitis?	3784	1371	5155
	What Are Pancreatic Stones and How Are They Treated?	3212	1783	4995
	How Will I Know if I'm Not Absorbing Nutrients Well?	3503	1353	4856
	What Are the Symptoms of Pancreatic Cancer?	3808	858	4666
	What Is Acute Pancreatitis and What Are Its Causes and Symptoms?	737	3847	4584
	Acute Pancreatitis: What Foods and Beverages Should I Avoid?	3465	717	4182
Patient videos	What Symptoms Did You Experience That Lead to Your Diagnosis of Acute Pancreatitis?	29,080	2566	31,646
	What Symptoms Lead to Your Diagnosis of Chronic Pancreatitis?	4871	1828	6699
	What Symptoms Lead to Your Diagnosis of EPI? How Was It Diagnosed?	1915	1158	3073
	After Your Initial Acute Pancreatitis Attack, Did You Go Back to Being Symptom-free?	1413	1571	2984
	After an Episode of Acute Pancreatitis, What Food and Beverages Do You Eat or Try to Avoid?	2108	403	2511
	How Do You Explain Acute Pancreatitis To Your Family and Friends?	421	1662	2083
	How Is Your Chronic Pancreatitis Managed and Treated?	937	972	1909
	What Disease Progression Did You Experience After Your Diagnosis of Chronic Pancreatitis?	550	1307	1857
	How Do You Explain Your Chronic Pancreatitis to Family and Friends?	493	1152	1645
	What Did You Know About The Pancreas Before Your Diagnosis, and What Do You Know Now?	172	1054	1226

TABLE 2. Top 10 Animations and Expert Videos by Highest Retention Viewed

Video Type	Video Title	
Animations	Exocrine Pancreatic Insufficiency Management and Treatment of Chronic Pancreatitis	
	Acute Pancreatitis Management and Treatment of Acute Pancreatitis	
	Pancreatic Cancer: Signs, Symptoms, and Risk Factors	
	The Role and Anatomy of the Pancreas	
	Chronic Pancreatitis	
	Pancreatic Cancer: Pathophysiology, Diagnosis, and Staging	
	Pancreatic Cancer: Treatment and Outcomes	
	Understanding ERCP	
	Expert videos	What Is the Link Between Alcohol and Acute Pancreatitis?
		How Can You Keep the Pancreas Healthy?
Acute Pancreatitis: What Foods and Beverages Should I Avoid?		
How Will I Know if I'm Not Absorbing Nutrients Well?		
What Are the Symptoms of Pancreatic Cancer?		
Chronic Pancreatitis: What Foods and Beverages Should I Avoid?		
How Is Acute Pancreatitis Treated?		
What Are Pancreatic Stones and How Are They Treated?		
What Are the Different Stages of Pancreatic Cancer?		
What Are the Risks of ERCP?		

Retention determined by the percentage of the total video length viewed.

“Pancreatic Surgery: Benefits, Risks, and Relevant Anatomy” (57,977 views) were the top animations viewed, respectively.

The most common expert videos viewed by the participants were “Chronic Pancreatitis: What Foods and Beverages Should I Avoid?”, “How Can You Keep the Pancreas Healthy?”, “How Is Acute Pancreatitis Treated?”, “What Are the Different Stages of Pancreatic Cancer?”, and “What Is the Link Between Alcohol and Acute Pancreatitis?” (Table 1).

Among the patient experience videos, “What Symptoms Did You Experience That Lead to Your Diagnosis of Acute Pancreatitis?”, “What Symptoms Lead to Your Diagnosis of Chronic Pancreatitis?”, “What Symptoms Lead to Your Diagnosis of EPI? How Was It Diagnosed?”, “After Your Initial Acute Pancreatitis Attack, Did You Go Back to Being Symptom-free?”, and “After an Episode of Acute Pancreatitis, What Food and Beverages Do You Eat or Try to Avoid?” were the most viewed, respectively (Table 1).

Animations and Videos With the Highest Viewer Retention

Table 2 lists the top 10 animations and top 10 videos by viewer retention (as determined by the percentage of the total video length viewed). “Exocrine Pancreatic Insufficiency” and “What Is the Link Between Alcohol and Acute Pancreatitis?” are the top animation and video that had the highest retention. For both these videos, 78% of each video’s content was viewed.

Participant Knowledge and Commitment to Change

Among participants who completed the online feedback survey (n = 4869), approximately 91% reported they learned new information, 84.6% learned new treatment options, and 83.2% learned new surgery options for pancreatic diseases. Most participants (>94%) also expressed a commitment to change in terms of using the information to better manage their pancreatic disease and indicated their intention to engage with their doctor in discussions (Fig. 3).

DISCUSSION

The data from our study show that NPF’s APP pancreas education modules had approximately 1.5 million views and approximately 548,000 unique participants during the 4-year study period. The most popular topic of the animations was “Role and Anatomy of the Pancreas,” and the most common expert video viewed was “Chronic Pancreatitis: What Foods and Beverages Should I Avoid?” Participants who completed the online feedback survey reported knowledge gains and commitment to change by indicating they would discuss a new option with their physician or implement a newly learned self-management action.

Several studies reported that low health literacy negatively impacts patients’ health outcomes,^{8–11} yet there are limited reliable educational resources specific to patient needs and interests in pancreatic diseases. The National Institutes of Health recommends a seventh- to eighth-grade reading level for easy-to-read health materials and the American Medical Association suggests fifth- to sixth-grade reading level for patient education print materials.^{11,18} However, current patient education content is predominantly text based and most often written at literacy levels above the comprehension level of laypersons in many areas of oncology including pancreatic cancer, palliative care, radiation oncology, internal medicine, and others.^{19–27}

National Pancreas Foundation’s *Animated Pancreas Patient—An Animated Patient’s Guide to Pancreatic Diseases* uses visual learning formats to address patient barriers to health literacy and provide an accessible, evidence-based resource. Multidisciplinary expert faculty guide content development of the APP website, which provides free access to educational content through succinct animations with audio narration of easy-to-understand, grade 6 to 8 level content, focusing on frequently asked questions and key disease concepts; short video segments of experts

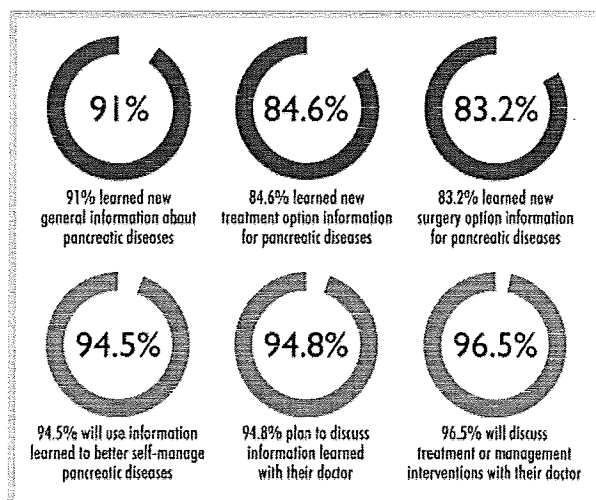


FIGURE 3. Patients who experienced improved outcomes.

answering questions; videos of patients sharing their experiences; and slide shows of content covered by the animations.¹⁵ The content of APP educational modules aligns with the health literacy literature on the effectiveness of visual aids and video in patient education.²⁸ The feedback survey on self-reported gains in competence and intention to change also align with Moore and colleagues²⁹ level 4 outcomes for continuing medical education.

Strengths of our study include a large user sample size, reaching a nationwide audience, benefiting from the guidance of a multidisciplinary expert faculty in the development of content, and sourcing shared disease experiences directly from patients. We believe that the competencies that patients gain through using the APP can help them more effectively participate in shared decision making, which promotes patient satisfaction with their health care experience.^{30,31} The multimedia learning components of the APP are also helpful for use among clinicians with busy schedules and lack of patient education resources. *Animated Pancreas Patient* is also in the process of developing content relevant for pediatric patients in a format suited to their learning needs. A mobile App (*Pancreas101*) was introduced in July 2016 and is freely accessible for use by patients. To address the needs of Spanish-speaking audience, the NPF has also produced an equivalent resource in Spanish in April 2015 (www.PancreasAnimado.com). New videos are being added, and efforts are being made to translate APP educational content into other languages to benefit global communities with pancreatic diseases.

The limitations of our study include retrospective design, use of self-reported responses from a relatively small group of users taking part in the optional feedback survey, and generalization of a fairly limited number of user comments. Although the APP received approximately 1.5 million views worldwide, only few (n = 4869) participated in the feedback survey. This is because the feedback survey was optional (no monetary compensation provided) for completing the survey. The program also lacked a formal presurvey/postsurvey for assessment. Because of the nature of the survey, we were also unable to find out which specific modules participants accessed.

In conclusion, *Animated Pancreas Patient—An Animated Patient's Guide to Pancreatic Diseases* effectively delivers education to patients with diseases of the pancreas. This visual format of learning demonstrates wide reach and has vast potential to improve health outcomes by informing patients and their caregivers. Continued efforts should be made to provide patient resources that address health literacy and patient education, responding to the needs of patients for better quality of life in pancreatic diseases.

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