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**Support for my video is support for me: A YouTube scoping review of videos
including adolescents with chronic pain**

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Abstract

Adolescents with chronic pain report feelings of social isolation, of being different, and lack of understanding from peers. These challenges suggest that these adolescents may not obtain the social support they require. Thus, they may have to find other venues through which to find social support. Adolescents are heavy users of social media as a venue to share experience and obtain information and adolescents with chronic pain may be no different.

A scoping review of YouTube was conducted by searching videos using the terms ‘youth with chronic pain’ and ‘teens with chronic pain’. Videos in English, targeting at and including an adolescent with chronic pain were included. All identified videos were screened for eligibility until 20 consecutive videos were excluded. For each included video the first 5 related videos suggested by YouTube were screened for eligibility. This selection process resulted in 18 included videos, with a total of 936 comments. Recurring themes in the videos’ comments were identified using qualitative content analysis.

Videos content mainly covered multidisciplinary treatment options, alternative treatments and impact of pain on daily life. While a variety of treatment options were discussed, details of treatment content were lacking. Comments reflected the overarching message “*you are not alone!*” and mainly focused on providing and receiving support, sharing suffering, and revealing the impact of pain on relationships and daily life.

Despite potential challenges associated with social media, YouTube may be a promising platform for provision of social support for adolescents with chronic pain.

Introduction

Chronic pain is highly prevalent in adolescents with up to 83% experiencing chronic headaches and up to 40% with abdominal pain [1]. Adolescents with chronic pain often feel isolated, withdraw from social gatherings and can miss school due to their condition [2,3]. This is concerning as a lack of social support has negative consequences on the individual's condition such as feeling less likely to cope with pain [4]. Therefore, it is in the interest of healthcare professionals to explore new ways for adolescents with chronic pain to gain the social interaction they often miss due to ill health.

Social media platforms are a new way for adolescents to socialise with others. These platforms allow users to connect with others worldwide, post their own creations and receive comments and ratings on their posts [5]. Social media is particularly popular among adolescents with 88% using at least one social media platform [6] and 22% checking their favourite platform several times a day [7]. Although there are numerous social media platforms available, one of the most used platforms by adolescents is YouTube; a video sharing platform where users can provide comments on the uploaded content [6]. By engaging with platforms such as YouTube, adolescents can create and strengthen social interactions and further explore their identity in ways unavailable offline [8,9]. For example, individuals may find others online with similarities to them that they have not found in face-to-face contacts [10]. Given that YouTube can be accessed anywhere with internet connection, it allows adolescents with chronic pain to interact with others without leaving their homes, thereby fostering access to otherwise inaccessible individuals, worldwide, who can empathise with their pain and provide support.

Although it can be argued that social media can benefit those with chronic pain in their social connection needs, there is little previous research exploring the idea. The limited evidence

available points out that pain-free adolescents report limited use of the Internet for seeking pain information and support. This limited use was mainly driven by the adolescents' mistrust of the posted information [11,12]. However, Ahola Kohut and colleagues (2018) identified that online information seeking is more common in adolescents with a chronic condition, with a focus on easy to access and understandable sites, despite the [accuracy of information on the site](#) [13].

Furthermore, despite the potential benefits of social media platforms to engage with likeminded others, this does not come without challenges. For instance, a challenge for social media platforms is the very nature of social media—an open platform—that allows individuals to post personal experiences (e.g. health/illness experiences) and offer advice regardless of the scientific evidence of the interventions contained in their personal experiences [14]. Another concern is that viewers are able to leave unfiltered comments and therefore represent a vulnerable environment for cyber victimization [14]. The aim of the current study was to conduct a scoping review of YouTube to identify how adolescents with chronic pain communicate about the challenges they face using YouTube.

MATERIALS AND METHODS

Study Design

A scoping review of YouTube videos was conducted based on Arksey and O'Malley's methodological framework for scoping studies [15] with additional search strategies and screening approaches appropriated for YouTube reviews [16]. Arksey and O'Malley's framework has been used to guide a scoping review of YouTube videos in previous research [17]. The four principle stages of the scoping review were to (i) identify relevant videos, (ii)

select videos, (iii) extract data, and (iv) collate, summarise and report results. The PRISMA statement checklist was used to ensure that the necessary data [were](#) represented [18].

Identifying Relevant Videos

The video search was conducted in June 2017 in Ottawa, Canada by two research assistants, and in Stirling, Scotland by one research assistant. A search was performed by all three research assistants for each of the following search terms: “*teens with chronic pain*” and “*youth with chronic pain*”. The search terms were selected based on Google Trends (Google, n.d. <https://trends.google.com/trends/>) by identifying the two most used terms for adolescents (e.g. teens [and](#) youth, [versus](#) teenager, adolescent, young people) and the most searched term for chronic pain (e.g. chronic pain versus persistent pain, ongoing pain, continuing pain) (see Figure 1). Each research assistant created a new YouTube account for [both](#) search terms to ensure that the search history did not influence the search results.

Insert Figure 1 Outcome of Google Trends Search here

Video Selection

Each video was screened in the order they appeared [on the main page of suggested videos in YouTube](#). The video was included if it: (1) was targeted at adolescents, (2) included an adolescent in the video (YouTube profiles of the person posting were screened to determine age), and (3) focused on chronic or persistent pain. Videos were excluded if the video (1) targeted adults, (2) targeted clinicians, (3) was a news clip, (4) was a product advertisement, (5) spoke about menstrual pain, (6) targeted parents, or (7) was not about chronic pain. If a video was included, we used the snowball technique to identify other relevant videos [16]. Our snowball

approach included the screening of the first five videos on the sidebar of ‘recommended videos’, which appears when a video is selected to view. The search using each of the two search terms was completed when 20 consecutive videos from the main page of suggested videos in YouTube (irrespective of the selection decision of the videos appearing in the sidebar) were excluded. To aid comparison across the research assistants’ searches and final selection of included videos, the research assistants documented all the URLs of the videos that were screened up to and including the 20 consecutively excluded videos. Screeners also documented if the video met inclusion criteria and if not, the reason for exclusion. The entire research team reviewed the list of videos that were included and excluded together. Any disagreements were discussed, and the videos were viewed by the research team to determine their inclusion or exclusion based on the criteria. The final set of included videos consists of 18 videos, with a total of 936 comments (See Figure 2).

Insert Figure 2 PRISMA Chart of Video Selection here

Data Extraction

Two research assistants conducted the data extraction of the final list of included videos in July 2017 and one research assistant extracted data from the comments on the included videos, to conduct an inductive content analysis [19]. A data collection form was created for the video data extraction in Microsoft Excel. The information extracted included, (1) video information (name of the video, search term, date posted, date retrieved, length, number of adolescents in the video, gender of adolescents in the video, name of organisation that created the video), (2) video rating

(view count, like/dislike count), (3) multidisciplinary treatment (pharmacological, physical, psychological treatments), (4) alternative therapies, and (5) daily life impact (school, social life).

Collating, Summarising and Reporting the Results

The data extracted from the videos were collated and summarised in Table 1. Additionally, the content of the comments were analyzed and major categories identified using inductive content analysis [19,20]. One research assistant (EM) took charge of this process, while discussing every step and decision taken in detail with a senior member of the research team (LC). In the first step of data familiarization, the research assistant (EM) read through all the comments without applying any patterns or codes to the data. After this first close read of the data, the coding phase started, which was data-driven to identify the meaningful passages of content within the data without applying any pre-existing theoretical framework or categorization. For this coding phase, all the comments were gathered together in one document without making a distinction as to which video the comments belonged. This allowed identification of meaningful passages within the comments independent of specific video characteristics. The research assistant generated codes during this first coding phase until all the data were coded, previously coded sections were re-analyzed to ensure new codes did not apply to those sections. The research assistant and senior researcher team member discussed the generated codes and discussed the next step of categorization. Categorization occurred by examining coded data for patterns, which could be collapsed into a more comprehensive unit of understanding but staying close to the data [20, 21]. During this stage, regular meetings between the research assistant (EM) and senior researcher (LC) allowed for discussions to ensure that all data were accounted for and any unresolved categorization of data so that agreement on categories was reached. Subsequently, all members of the research team reviewed the content of

categories to ensure that the categories were grounded in the data and provided suggestions for revisions, which included merging and renaming categories. This final set of categories was re-reviewed with the dataset as a whole to ensure all comments were accounted for and quotations were included to help illustrate each category.

Insert Table 1 here

Ethics

Approval from an ethics committee was not necessary, as the videos and comments used in this scoping review were only those that could be obtained from a public search and thus treated as publically obtainable documents (Smedley & Coulson, 2018). The policies of YouTube describe public videos as videos that are available for anyone to see whereas private videos are only viewable to subscribers to the poster's YouTube channel (YouTube, 2018 https://support.google.com/youtube/answer/157177?hl=en&ref_topic=2803240). To ensure the confidentiality of each comment used in this study, we followed the guidance by Smedley and Coulson (2018): each selected comment was entered into both Google and YouTube search bars to determine if they were able to be located using these simple search strategies. None of the comments were returned or traceable from these simple searches. We have also not included any explicit data to link the comments with a specific video and have made edits to some comments to further protect commenters' identity (Smedley & Coulson, 2018).

RESULTS

The results are divided into two sections; the first section provides the description and characteristics of the videos and the second section provides the qualitative content analysis of the comments.

Video Description

Eighteen YouTube videos met the inclusion criteria and were found using the search term “*teens with chronic pain*” (see Table 1). No new videos were found using the search term “*youth with chronic pain*”. The videos were posted between October 5, 2011 and September 1, 2017, with most of the videos being posted in 2015 (n= 5) and 2016 (n=4). The majority (n=10) were posted by pediatric hospitals, with two posted by foundations, one by a clinician/researcher, and five by adolescents themselves. Most were posted in the United States (n=10), three from Canada, three from the United Kingdom, and two videos that did not provide location details. The time length of the videos ranged from 2:15 minutes to 12:33 minutes. The shortest video was posted by a pediatric hospital and the longest by an adolescent with chronic pain. The number of views ranged from 50 to 58,174. The highest view count was for a video created and posted by an adolescent in 2016.

The number of adolescents in the video ranged from 1 to 9 with the largest number in a video created and posted by an adolescent, which was announced as a trailer for her upcoming documentary on chronic pain. A total of 47 different adolescents were featured in the videos of which only 7 were males. No males posted their own video and only one male appeared in a video created and posted by an adolescent. Most of the videos did not focus on a specific type of chronic pain; however one video did focus on Ehlers Danlos, and two videos focused on Complex Regional Pain Syndrome.

In terms of treatment, across all videos a range of treatment options are discussed; however very little detail about what treatment involved was provided. Three of the videos explicitly mentioned types of *medication* (e.g. opioids, anti-anxiolytics) and only one of these was a video produced by a health centre. Eleven of the people in the videos did not mention medications despite the adolescents in these videos stating that they were under the care of a physician. Over half of the videos (n= 11) included comments about working with *psychologists* with some providing specifics like guided imagery, breathing techniques, and acceptance therapy. All but three videos included comments on working with a *physiotherapist*, citing the benefits of doing some form of exercise. Only five videos included some reference to *alternative therapy* such as herbal substances (e.g. devil's claw) and two of the videos mentioned that the inclusion of care from a chiropractor (see Table 1 for details). Two videos included the importance of religion or spirituality on the adolescent's coping with chronic pain.

With respect to how pain impacts the adolescent's life, eight of the adolescents in the videos explicitly mentioned school and/or extracurricular activities with the most of this talk focused on having to give up activities due to their chronic pain. Only two discussed how treatment has made a difference to their school attendance. Fourteen of the videos included the impact that chronic pain has had on the adolescents' social life. All but two of these touched on the negative effects of chronic pain on socialization as these adolescents talked about being isolated from friends, friends not understanding or not believing the adolescent about their chronic pain condition and feeling lonely. The two videos that included a more positive message about socializing with peers spoke of the benefit of meeting another with chronic pain as they felt understood but did not elaborate as to whether this was beneficial in terms of social functioning.

Comments Description

The amount of comments per video ranged from 0-766, with a median of 1 and average of 52 comments per video. The main message across all comments and associated categories reflected the appreciation for sharing stories, either through the posted video or posted comments, which made people feel that they are not alone in their pain journey. All of the categories identified across all comments reflect this overarching message “*you are not alone!*” and can be categorized as: 1) Providing and receiving support; 2) Sharing suffering; and 3) Impact on relationships and daily life.

Providing and Receiving Support

A large number of posted comments revealed the crucial need of adolescents with chronic pain for social support both emotional (specifically validation) and information seeking. Some commentators simply thanked the creator of the video without themselves seeking support/sharing any information about themselves.

“Thank you for this! Very much needed!”

Providing emotional support through posting encouraging messages towards the creator of the video or other people who had posted their pain journey in the comments was the most frequently observed type of social support.

“I am so grateful that someone has gone through the same thing and is coming out on the other side. Thank you.”

“Hey really sorry to hear you going thru such hard time in life. Many of us here are willing to listen. Hope you feel better now by typing it all out! :)”

“This is amazing! Thank you for speaking out and explaining this for those who experience the same sort of thing and for those who may not understand what it is like.”

Several comments also disclosed that the positive feedback and emotional social support provided by the videos and the comments was not limited to adolescents with chronic pain but stretched to adolescents with other chronic illnesses (e.g. diabetes) or mental health problems (e.g. depression or anxiety). These comments expressed feeling supported through engaging with the video and often involved sharing experiences of their struggle and their appreciation for the video.

“I am currently suffering with depression and when I feel down watching your videos always makes me feel better about myself and more confident in myself.”

“I moved across America and was diagnosed with [chronic condition name] within [time period] of each other, and it's so easy to get caught up in the negativity of a situation.”

Several comments illustrate that people who viewed the videos were seeking informational social support (e.g. strategies to cope) but only directed their comments to the video creator as opposed to others in the comment list. Some questions were from pain-free people interested in understanding how they should support their friend who has chronic pain. It is important to note, that in one of the included videos the creator of the video explicitly asked for observers to post questions they would like to see addressed in an upcoming video. However, not all of the postings about informational support were for this one video.

“How did your [sibling] accept your condition and how [do they] feel about it?”

“How would you want a friend who is worried that talking with you on a particularly bad [pain] day is making it worse, when you've already said that you're okay to talk and have a conversation with, despite the [pain condition]?”

Sharing Suffering

While social support reflects a large quantity of the posted comments an equally large number of comments reflected viewer's sharing their own suffering and difficulties in finding effective coping mechanisms for dealing with chronic pain. For instance, several commenters shared a detailed description of their own painful condition and pain journey. The coping strategies posted covered a range of strategies towards chronic pain, by including information on strategies they found effective such as medication, herbal remedies, diet and psychological strategies (e.g. taking responsibility or thinking positively). However, commenters also shared how the journey to reach acceptance, or find effective coping strategies can be a struggle, with some still seeking help.

"Then I found anti-inflammatories. 15 to 30 minutes and the [pain] is gone. But you have to take [dose]. Stay strong....."

"What I found to be pretty helpful (to me at least) is I take [herbal product] pills per day to manage the pain, which helped me reduce the amount of painkillers I used to take by taking something natural instead. I also took [herbal product] and it really helped but I stopped because swallowing those huge ass pills was a drag but now I'm starting to see how much they've helped me when I took them... I guess I should go back to taking them now."

"Taking responsibility and accepting reality as a thing we can affect is the first step to getting even just a little bit better."

Furthermore, various posts demonstrated how people with chronic pain continue to compare their life before and after pain symptoms started. Many of these comments identified that adolescents with chronic pain wish for their life without pain while others comment on how they have come to accept that life is different now.

"But the worst of it is when my pain stops me from doing the things I love/once loved."

"I'm still in pain and I don't think that will ever go away but it's a much more bearable level of pain. I do have my bad days though and sometimes weeks but I no longer have months of unbearable pain. But I find once you accept that this is your reality and you will most likely never be normal, it makes dealing with it somehow more better. I know it sounds hopeless but for me accept that ... it is like accepting that I will always have [color] eyes. It's what I was born with and that's that . Once I accepted that I could focus on strategies of dealing with my pain."

Impact on Relationships and Daily Life

In sharing their stories, the commenters to videos acknowledged how the experience of chronic pain impacts their daily life especially in relation to school/work and their various relationships. Comments highlight how devastating chronic pain has been on their social roles particularly school-related activities or work responsibilities.

"It's frustrating to not be able to work or go to school for as long as I need to, I work with people far older than me ... and don't have these issues."

"I missed class a lot growing up because I was sick constantly, and I fell behind a lot of times so I had to push through to pass every single school year, which made me more stressed than I already was."

The comments also reveal that within their social lives there was variation in the level of family and friend support they received with many receiving a high degree of support while others indicate feeling like a burden on their friends and family.

"...it helps when I have a Support group like family and friend's."

"What annoys me most is the fact that I'm unable to tell my peers about it."

“It is easy to let the burden I am carrying make me think I am a horrible burden to others, even now that I am pretty much recovered from my mental stuff, it still makes me feel depressed thinking about the amount of work my teachers and parents go through to try and support me when I am so absent.”

While there were a few positive postings about their experiences with health care professionals (e.g. physicians, nurses, psychologists), most share negative experiences with commenters perceiving that health care professionals did not understand them.

“...but the experiences I have had with doctors weren't helpful and actually only more disheartening.”

“It's very difficult for me because finding help is impossible. [Specialist] won't listen to my psychological symptoms....”

“Don't give up on the doctors people, they really do know what they are doing...”

Lastly, unlike the support most commenters received from friends and family, they felt that society's lack of chronic pain knowledge can negatively impact an adolescent.

“...and it's so hard to find people who understand and don't give wild unsolicited advice like "wrap this rock around your head and go for a walk", "eat a lemon" ... ??? Haha.”

“I hate it when people take me as [totally disabled], I should know what I can and can't do right? And if I don't I will know in [a few days] and will never do it again and when teachers hover over me I'm thinking "if I need your help I'll ask so go away" but there is no nice way of saying that. I don't like it when people make me stand out more than I have to like I won't fall down and brake an arm if I walk in a crowded hallway.”

DISCUSSION

Social media (e.g. YouTube) is a mainstay in the lives of adolescents worldwide and has been suggested as a way to communicate shared experiences and seek information and support [22]. Adolescents with chronic pain are no different. Indeed, the Internet has become an accessible platform to seek health related information [11,12,13] but the open nature of social media platforms induces new challenges such as the evidence-based composition of the posted advice and risk of cyber-bullying. However, the majority of video posts in this review did not suggest that evidenced informed interventions (pharmacological, psychological, physical, social/school) were unhelpful nor did they contain significant amounts of non-evidence-based interventions. Some videos contained suggestions for alternative approaches such as herbal remedies (e.g. devils claw) and spirituality. Nevertheless, videos that included alternative approaches did not solely focus on these types of approaches and approached them rather as additional options to more traditional treatments.

Moreover, there was no evidence in the comments to video posters or other commenters of victimizing comments. Rather, the main message in the videos posted by adolescents with chronic pain were more affirming in nature and encouraging to viewers who were living with chronic pain or chronic illness as opposed to focusing solely on what you need to do to treat pain. Affirming messages (e.g. acknowledging the difficulty of living with pain) and sharing of suffering experiences (e.g. being disbelieved by peers and others) were the most appreciated content as illustrated by viewers posted comments. The importance of receiving and sharing feelings of belonging and acknowledgement of their pain experience as real confirms findings from other research exploring the benefits of peer support [23,24].

Similar to other studies that examine engagement with peer-based social support for adolescents with chronic pain [23] those who posted videos were mostly female. Only one video

posted by an adolescent with chronic pain included a male adolescent with chronic pain. It may be that the nature of social sharing, especially of personal challenges such as the emotional distress of living with chronic pain, may appeal more to adolescent girls as their friendships are characterized more by emotional sharing. In contrast, male adolescent friendships are more characterized by physical presence [25]. Moreover, society's view of masculinity may be a barrier to seek out online forums for health and peer social support. Research on men's health has found that men less often attend self-management groups, where emotional support types of peer support occurs, as they are not viewed as action orientated and may conflict with society's view of men as stoic, independent, and in control [26]. Given that adolescent boys are developmentally being socialized to adopt a masculine profile [27], adolescent boys may be even more apt not to engage in social sharing of emotional content in order to fit within social norms. A recent qualitative study exploring adolescents with chronic illnesses use of online platforms for health-related information and peer support [13] had 64% (n=21) female participants, so although helpful, the results may not accurately reflect the needs of adolescent boys. Thus, an understanding of the nature of the social support and sorts of health-related information different adolescents with chronic pain are seeking on social media is needed in order to leverage the advantages of social media as a forum for health-related information and peer support.

Based on 'like' counts and comments adolescent-produced videos were more popular compared to videos produced by clinicians/hospitals. This may not be surprising as Ahola Kohut and colleagues (2018) found that adolescents would access sites, which were easy to access and understand over those that may be more creditable [13]. Similarly, in this study we found that adolescents were more engaged with the content contained in adolescent posted videos, which may have been viewed as easier to understand. Alternatively, adolescents may find videos posted

by others as more credible due to lived experience of the posters, thereby instilling trust and confidence [12]. Regardless, this observation highlights the need for patient engagement in creating powerful and effective social media messages. Researchers and clinicians interested in using online platforms, such as YouTube, for broad reach to adolescents with chronic pain may benefit from engaging adolescents in the content, portrayal, and production of videos.

Our overview table (See Table 1) is an easily accessible source to assist healthcare professionals looking for advice on which YouTube videos to recommend to their patients, depending on what support the adolescents need. Having such resources available, regularly updated, and not limited to just YouTube posts, could prevent adolescents from broadly exploring the internet for support and having to determine for themselves what is useful and trustworthy [12]. Furthermore, in providing these recommendations healthcare professionals have the opportunity to guide adolescents on how to deal with the potential negativity they might experience in using social media. While our overview table (see Table 1) can be a first step in this direction, it is worthwhile to note that due our **exclusion** criteria, **some** videos with relevant information did not make the selection. For example, whiteboard illustration videos (https://www.youtube.com/watch?v=C_3phB93rvI) about pain and Elliot Krane's Ted Talk entitled "The mystery of chronic pain" (<https://www.youtube.com/watch?v=J6--CMhcCfQ>) were identified in our search but were excluded as these videos did not include an adolescent. Nevertheless, they represent important sources of information and affirmation of the legitimacy of chronic pain but lack the credibility of one living with chronic pain.

Taken together, in contrast with research in pain-free adolescents [11], our findings suggest that adolescents do use the Internet (at least YouTube) to gain information and/or support on pain management. However, this group of adolescents actively using YouTube for pain

management might be a specific subgroup of adolescents who are lacking other sources of support [11], thereby limiting generalizability to all adolescents with chronic pain. As we were unable to identify detailed characteristics of the YouTube posters and commenters, future research would benefit from identifying who exactly uses social media as a source of pain management support, exploration of how exactly social media benefits them and whether and how it can be incorporated within an interdisciplinary pain management approach.

To our knowledge this is the first scoping review of social media content, specifically YouTube, for and by adolescents with chronic pain. Nevertheless, there are limitations to our study. First, all videos contained English only content and all but 2 adolescents (appearing in the same video) were Caucasian. Yet YouTube is used worldwide thus we do not know if there are language and/or cultural differences in the content of videos in countries where English is not the predominant language. [Related to this, while we used an data-driven, inclusive, data extraction sheet, some relevant information about the videos \(e.g. setting, affective tone, ...\) might not have been gathered that can give more insight into the type of videos that were selected.](#) Second, although we followed recommendations for conducting scoping reviews of YouTube [16], there are limitations in how YouTube and Google search content. For instance, users cannot target Google searches to specific countries as the company removed the location search filter from their list of search options, which means that searches through Google are somewhat based on one's location. To partly overcome this limitation, our search was conducted in both Canada and the UK. All videos appeared in both searches and no videos were unique to the UK or Canada. [Furthermore, Google trends are based on terms used at the population level and thus we do not know if these are the same terms that adolescents use in searching for these types of videos.](#) [However, our intent was to find all the relevant videos as opposed to those that an adolescent](#)

with chronic pain may find. Third, YouTube is just one social media platform. Undoubtedly there are differences in what is posted on YouTube compared to other popular platforms amongst adolescents such as Snapchat and Instagram [6]. Posters on YouTube have to create content, a video, and then post the video. This creating process induces a time delay between the desire to post content and the actual posting, which may alter what they ultimately post. This is in contrast with other platforms, such as Snapchat and Instagram, which allow for more in the moment, instant sharing and therefore could present a different experience for both posters and viewers.

Despite these limitations, social media presents a robust milieu to disseminate knowledge to adolescents with chronic pain. Although this medium is being used by clinicians and adolescents there is limited research on how best to harness the medium for maximum benefit. Our findings suggest that videos produced by the adolescents were viewed more often and received more comments and likes than those produced by professionals. Consequently, future development of content needs to include adolescents as part of the team. Patient engagement research strategies have been developed to ensure the inclusion of those living with chronic pain to set research priorities [28]. Similar approaches are needed to the development of social media content targeting adolescents with chronic pain. The themes identified in the comments provide a first glimpse into what adolescents living with chronic pain are looking for when they engage with social media: affirmation, sharing of experiences, encouragement, belonging, and coping with the impact on daily life are preferred content. Although, YouTube has mechanisms for viewers' further engagement (e.g. comments, likes) with the video poster and other viewers the overall engagement with these activities (likes, comments) was limited compared to view count of the videos. This may not be any different than for other YouTube videos however it is unclear how these sorts of viewer activities impact the posting adolescent's feelings of support given that this

may be one of the drivers for why adolescents with chronic pain post videos. A systematic review examining the effects of social media and adolescent wellbeing found that most studies reported either mixed or no effect on adolescent well being however the included studies that examined interpersonal relationships and social support reported mostly positive outcomes (Best, Maktelow, & Taylor, 2014). Further research will be needed to determine how content on YouTube (videos, likes, comments) or other social media platforms influences outcomes such as school or social outcomes, loneliness, emotional well being, acceptance and coping with pain.

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Table 1: Overview of the data extracted from the videos

Video Information	Video Rating	Multimodal Treatment	Alternative Therapies	Daily Life Impact
<p>https://www.youtube.com/watch?v=EsWMc30OUEQ Name of Video: How Do You Cope with Chronic Pain? Search Term: teens with chronic Pain Date Posted: September 19th, 2013 Date Retrieved: September 1st, 2017 Length of Video: 4:20 Number of Teens in Video: 4 Gender of Teens in Video: 3 Females, 1 Male</p> <p>Hospital Created: The Marfan Foundation</p> <p>Country: United States</p>	<p>View Count: 1615 Like Count: 13 Dislike Count: 0 Comments : 0</p>	<p>Pharmacological : Medications help a lot with back pain (not named).</p> <p>Physical Therapy: Acupuncture, acupressure slow manipulation; stated all worked well.</p> <p>Psychological Therapy: N/A</p>	<p>Fish oils</p> <p>Vitamin E, D, C</p> <p>Devils Claw.</p> <p>Chiropractors did not help with back/joint pain.</p>	<p>Social Life: Friends do not understand pain</p> <p>School/Extracurricular: N/A</p>
<p>https://www.youtube.com/watch?v=7TZdVZ_XbHQ Name of Video: Chronic pain at UCLH Search Term: teens with chronic pain Date Posted: August 16th, 2013 Date Retrieved: September 1st, 2017 Length of Video: 4:15 Number of Teens in Video: 3 Gender of Teens in Video: 3 Females</p> <p>Hospital Created: University College London Hospital NHS Foundation</p> <p>Country: United Kingdom</p>	<p>View Count: 2758 Like Count: 21 Dislike Count: 2 Comments : 2</p>	<p>Pharmacological : N/A</p> <p>Physical Therapy: helped with sleeping position and writing letters to the school of what is possible and what not.</p> <p>Physiotherapist advises to relax shoulders, take deep breaths and do what you can.</p> <p>Hydrotherapy</p> <p>Psychological Therapy: Appointments with psychologist helped with understanding that I am still normal, and realising that everything needs to be pre-planned.</p> <p>Holistic approach, which also includes occupational therapy, social work and physicians.</p>	<p>Alternative Therapies</p>	<p>Social Life: Lost friends because she couldn't participate in social/leisure/sport activities due to her pain.</p> <p>Keeping a smile, having a positive attitude and talking to other people helps.</p> <p>School/Extracurricular: Gave up basketball and gymnastics due to pain.</p>

<p>https://www.youtube.com/watch?v=v-iXegXjHt0</p> <p>Name of Video: Living with Chronic Pain Search Term: teens with chronic pain Date Posted: May 18th, 2016 Date Retrieved: September 1st, 2017 Length of Video: 8:51 Number of Teens in Video: 1 Gender of Teens in Video: 1 Female</p> <p>Country: N/A</p>	<p>View Count: 58174 Like Count: 3379 Dislike Count: 40 Comments : 766</p>	<p>Pharmacological : Took pain medications in high school that made her feel worse and tired (did not name).</p> <p>Physical Therapy: Stressed the relevance of exercise, pacing, eating well, good sleeping pattern.</p> <p>Psychological Therapy: Cycle of pain and depression ("they go hand in hand")</p> <p>Acceptance of disease and not feeling sorry for herself to help her take responsibility and care for herself.</p> <p>Monitoring attitude and taking it 1 day at a time and do not let pain define you.</p>	<p>Spoke to the lord and developed a spiritual side to help her cope.</p>	<p>Social Life: Felt isolated and dropped out of school to study at home.</p> <p>Spoke of how she felt different from friends.</p> <p>Recognized social isolation was not good.</p> <p>School/Extracurricular: Was behind in school and was still finishing high school when her friends were finishing college.</p> <p>Life is a daily struggle.</p>
<p>https://www.youtube.com/watch?v=RmL7ccDa99I</p> <p>Name of Video: Tell me a story: Managing chronic pain from Ehlers Danlos syndrome Search Term: teens with chronic pain Date Posted: November 12th, 2012 Date Retrieved: September 1st, 2017 Length of Video: 2:57 Number of Teens in Video: 1 Gender of Teens in Video: 1 Female</p> <p>Hospital created: Cincinnati Children's Hospital Medical Centre.</p>	<p>View Count: 19741 Like Count: 89 Dislike Count: 2 Comments : 8</p>	<p>Pharmacological : Went to a pain clinic and a headache clinic but medication not mentioned</p> <p>Physical Therapy: Worked with physiotherapist but no details of the</p>	<p>N/A</p>	<p>Social Life: Stayed in bed all day when she had pain, not able to socialize.</p> <p>School/Extracurricular: Physician suggested to keep a balance between what she enjoys and how much she can handle with dance and theatre.</p>

Country: United States		interventions. Psychological Therapy: N/A Treatment was described as a holistic process. <i>'Don't let pain control your life'</i> emphasized as the main message.		
https://www.youtube.com/watch?v=ZN7Pmiu14QA Name of Video: Dancing with Pain (trailer) Search Term: teens with chronic pain Date Posted: October 19 th , 2013 Date Retrieved: September 1 st , 2017 Length of Video: 3:15 Number of Teens in Video: 5 Gender of Teens in Video: 4 Females, 1 Male, Clinician Created: Dr. Leora Kuttner Country: Canada	View Count: 2692 Like Count: 15 Dislike Count: 1 Comments : 1	Pharmacological : Worked with a physician but no details of the interventions. Physical Therapy: Stated the involvement of a physiotherapist but not what interventions were done. Stated the involvement of a massage therapist but no specifics of what type of massage. Psychological Therapy: Self-hypnosis Breathing techniques Visualisation Body scanning technique.		Social Life: Friends were only there when teen was healthy. Teen mentioned that reactions from other people towards the painful episodes can be worse than the pain itself. School/Extracurricular: N/A General: It is very tiring, getting out of bed is most painful part of the day.
https://www.youtube.com/watch?v=uWqjR0Rmfqw Name of Video: INCONVENIENT: A Documentary on Chronic Pain (trailer) Search Term: teens with chronic pain Date Posted: February 25 th , 2017 Date Retrieved: September 1 st , 2017 Length of Video: 3:19 Number of Teens in Video: 9 Gender of Teens in Video: 8 Females, 1 Male Country: creator's country Canada	View Count: 566 Like Count: 10 Dislike Count: 0 Comments : 2	Pharmacological : N/A Physical Therapy: N/A Psychological Therapy: N/A	N/A	Social Life: Hard to talk about the pain and describe it to others in a way they can understand, making relationships difficult. School/Extracurricular: N/A General: Simple, everyday tasks are difficult. At its worst: couldn't get out of bed on her own.
https://www.youtube.com/watch?v=-aaiT8gvaLQQ	View Count: 494	Pharmacological : Pain physician		Social Life: People don't understand, they

<p>Name of Video: Acupuncture, Hypnosis Reduce Chronic Pain in Teens Search Term: teens with chronic pain Date Posted: August 27th, 2016 Date Retrieved: September 1st, 2017 Length of Video: 2:37 Number of Teens in Video: 1 Gender of Teens in Video: 1 Male</p> <p>Hospital Created: Seattle Children's hospital Country: United States</p>	<p>Like Count: 1 Dislike Count: 0 Comments : 1</p>	<p>uses acupuncture as another intervention because most of the medication have side effects.</p> <p>Physical Therapy: Orthotics</p> <p>Psychological Therapy: Image visualisation</p> <p>Treatment was described as a life-changing resource by parent.</p>		<p>simply think you need to 'suck it up' or they see you as weak.</p> <p>Entire societal culture of understanding pain needs to change.</p> <p>School/Extracurricular: N/A</p>
<p>https://www.youtube.com/watch?v=KALNaDRFSik</p> <p>Name of Video: Chronic Pain Program, Children's Specialized Hospital- Leah's experience Search Term: teens with chronic pain Date Posted: July 27th, 2015 Date Retrieved: September 1st, 2017 Length of Video: 3:22 Number of Teens in Video: 1 Gender of Teens in Video: 1 Female</p> <p>Hospital Created: Children's Specialized Hospital Country: United States</p>	<p>View Count: 1291 Like Count: 4 Dislike Count: 0 Comments : 1</p>	<p>Pharmacological : N/A</p> <p>Physical Therapy: Hospital physical therapy program; it was hard as they pushed her but helped gain her life back.</p> <p>Psychological Therapy: Worked with psychologist throughout process to learn coping and life skills but no details of the interventions.</p> <p>Worked with child life development nurse but no details of the interventions.</p>	<p>N/A</p>	<p>Social Life: Felt lonely</p> <p>School/Extracurricular: N/A</p>
<p>https://www.youtube.com/watch?v=VXqHRYWYk3A</p> <p>Name of Video: Helping Children Who Have Chronic Pain, St Louis Children's Hospital Search Term: teens with chronic pain Date Posted: May 14th, 2015 Date Retrieved: September 1st, 2017 Length of Video: 2:30 Number of Teens in Video: 2 Gender of Teens in Video: 2 Female</p> <p>Hospital Created: St Louis Children's Hospital</p>	<p>View Count: 648 Like Count: 5 Dislike Count: 0 Comments : 0</p>	<p>Pharmacological : Worked with a nurse practitioner but medication not mentioned</p> <p>Physical Therapy: Worked with physiotherapist but no details of</p>	<p>N/A</p>	<p>Social Life: N/A</p> <p>School/Extracurricular: Unable to attend school because the pain is so bad.</p> <p>Only performs life activities after assessing pain level on a daily basis.</p>

<p>Country: United States</p>		<p>the interventions.</p> <p>Psychological Therapy: Worked with psychologist but no details of the interventions.</p> <p>Care team was described as phenomenal and amazing.</p>		<p>General: Life has completely changed.</p>
<p>https://www.youtube.com/watch?v=Y8ZH6myRfeg Name of Video: Chronic Pain CTA Search Term: teens with chronic pain Date Posted: November 21st, 2012 Date Retrieved: September 1st, 2017 Length of Video: 6:27 Number of Teens in Video: 7 Gender of Teens in Video: 6 Females, 1 Male</p> <p>Organization Created: ICL Foundation</p> <p>Country: Canada</p>	<p>View Count: 1461 Like Count: 8 Dislike Count: 1 Comments : 0</p>	<p>Pharmacological : Physician didn't believe us.</p> <p>Physical Therapy: N/A</p> <p>Psychological Therapy: N/A</p>	<p>N/A</p>	<p>Social Life: Lost many friends as could not participate in the things they were doing due to the pain.</p> <p>You can't really go out as you're tried all the time, which is lonely.</p> <p>Hard to find people to talk to because a lot of people's reaction to pain is negative..</p> <p>People think they know what you're going through but they don't and they don't <i>want</i> to understand.</p> <p>It helps to find someone who understands what you are going through.</p> <p>Need to have a peer support network. Find someone who goes through the same thing makes you feel better as you have someone to talk to.</p> <p>Engaging with ICL foundation provides guidance and support.</p> <p>School/Extracurricular: Had to give up cheerleading and physical activities because of pain.</p>
<p>https://www.youtube.com/watch?v=rai-24Fv1pY Name of Video: Chronic Pain Program at Children's Specialized Hospital Search Term: teens with chronic pain Date Posted: January 29th, 2015 Date Retrieved: September 1st, 2017 Length of Video: 2:15 Number of Teens in Video: 3</p>	<p>View Count: 1196 Like Count: 2 Dislike Count: 0 Comments : 1</p>	<p>Pharmacological : N/A</p> <p>Physical Therapy: Physiotherapist helped with aquatherapy</p>	<p>N/A</p>	<p>Social Life: N/A</p> <p>School/Extracurricular: N/A</p>

<p>Gender of Teens in Video: 2 Females, 1 Male</p> <p>Hospital Created: Specialized Children's Hospital</p> <p>Country: United States</p>		<p>Worked with occupational therapists but no details of the interventions</p> <p>Psychological Therapy: N/A</p>		
<p>https://www.youtube.com/watch?v=7aV5IjrEnDs</p> <p>Name of Video: Pediatric Pain Program- Nemours Children's Hospital</p> <p>Search Term: teens with chronic pain</p> <p>Date Posted: March 23rd, 2014</p> <p>Date Retrieved: September 1st, 2017</p> <p>Length of Video: 5:31</p> <p>Number of Teens in Video: 1</p> <p>Gender of Teens in Video: 1 Female</p> <p>Hospital Created: Nemours Children's hospital</p> <p>Country: United States</p>	<p>View Count: 2823</p> <p>Like Count: 10</p> <p>Dislike Count: 0</p> <p>Comments : 0</p>	<p>Pharmacological : N/A</p> <p>Physical Therapy: Worked with physiotherapist but no details of the interventions.</p> <p>Worked with occupational therapists but no details of the interventions.</p> <p>Psychological Therapy: Behavioural therapy for emotional and sensory component. Guided imagery Breathing exercises. Teaching patients about pain signals and how to manage them. Setting goals</p>	<p>N/A</p>	<p>Social Life: N/A</p> <p>School/Extracurricular: Not able to go to school due to pain.</p> <p>Could not play basketball, or dance.</p> <p>Now back to playing basketball and planning to do softball.</p>
<p>https://www.youtube.com/watch?v=IKngXdH2f2Y</p> <p>Name of Video: Courtney's story- Mayo Clinic Pediatric Pain Rehabilitation Program</p> <p>Search Term: teens with chronic pain</p> <p>Date Posted: Jul 1, 2015</p> <p>Date Retrieved: September 1st, 2017</p> <p>Length of Video: 6:22</p> <p>Number of Teens in Video: 1</p> <p>Gender of Teens in Video: 1 Female</p> <p>Hospital Created: Mayo Clinic</p> <p>Country: United States</p>	<p>View Count: 3212</p> <p>Like Count: 19</p> <p>Dislike Count: 0</p> <p>Comments : 2</p>	<p>Pharmacological : Physician prescribed medications but the medications did not help with her pain.</p> <p>Physical Therapy: Physical therapist for acupuncture.</p> <p>Worked with occupational therapists but no details of the interventions.</p> <p>Psychological Therapy: N/A</p>	<p>Chiropractic therapy</p> <p>Use of spirit and religion to cope with pain.</p>	<p>Social Life: Parents would do things for her.</p> <p>School/Extracurricular: Enjoys doing extracurricular activities such as dance, exercise, basketball or running since treatment.</p>

		The multidisciplinary teamwork and support was described as crucial. Stated that they push you, it is hard.		
https://www.youtube.com/watch?v=Bb1fHxfjdWI Name of Video: Little Stars- Treating Chronic Pain in Children Search Term: teens with chronic pain Date Posted: July 7 th , 2015 Date Retrieved: September 1 st , 2017 Length of Video: 8:37 Number of Teens in Video: 2 Gender of Teens in Video: 2 Females Hospital Created: Children's Hospital and Clinic of Minneapolis. Country: United States	View Count: 1109 Like Count: 6 Dislike Count: 1 Comments : 0	Pharmacological : Worked with a pain physician but no details of medications. Physical Therapy: Exercise Personal trainer Psychological Therapy: Hypnosis Distraction techniques (Biofeedback) Breathing exercises Progressive muscle relaxation Pain psychologist advised to normalise life. Worked with a nurse practitioner and social worker but no details of interventions.	N/A	Social Life: N/A School/Extracurricular: Patient exercises to keep active.
https://www.youtube.com/watch?v=Ms4ys9wA5P1 Name of Video: Pediatric Pain Rehabilitation Search Term: teens with chronic pain Date Posted: October 5 th , 2011 Date Retrieved: September 1 st , 2017 Length of Video: 4:44 Number of Teens in Video: 3 Gender of Teens in Video: 2 Females, 1 Male Hospital Created: Cleveland Clinic Country: United States	View Count: 961 Like Count: 5 Dislike Count: 0 Comments : 0	Pharmacological : Physicians tried nerve blocks, epidurals, opioids but none of them helped with the teens' pain. Physical Therapy: Exercising, swimming Psychological Therapy: Positive outlook The inpatient 2-week programme was described as	N/A	Social Life: Inpatient unit provided support group that was very helpful and understanding. School/Extracurricular: Was unable to do activities and would just lay in bed and watch TV all day. With correct treatment, now able to snowboard, play basketball, football, baseball and video games.

<p>https://www.youtube.com/watch?v=fIHd5noWISw</p> <p>Name of Video: Chronic Regional Pain or RSD Search Term: teens with chronic pain Date Posted: October 18th, 2016 Date Retrieved: September 1st, 2017 Length of Video: 10:12 Number of Teens in Video: 2 Gender of Teens in Video: 2 Females</p> <p>Country: United Kingdom</p>	<p>View Count: 257 Like Count: 10 Dislike Count: 0 Comments : 13</p>	<p>draining.</p> <p>Pharmacological : Codeine did not help with the pain</p> <p>Physical Therapy: Worked with a physiotherapist in group but no details of interventions. Hot water bottle or bath for pain.</p> <p>Psychological Therapy: Working with a psychologist. Breathing techniques Talking to people Stay positive</p>	<p>Asked parents to put ice water on her when first started for the burning sensation- did not help</p>	<p>Social Life: People don't understand what it is like living with chronic pain. Restricts going out with family and friends</p> <p>Condition also affects family because they feel they can't help her or touch her with the pain.</p> <p>People said her pain was fake.</p> <p>School/Extracurricular: Can't wear pants some days because it is too painful, too hard to get dressed and go out with friends.</p>
<p>https://www.youtube.com/watch?v=r0oYxhnVQsM</p> <p>Name of Video: CRPS and Chronic Pain Awareness video Search Term: teens with chronic pain Date Posted: January 8th, 2015 Date Retrieved: September 1st, 2017 Length of Video: 4:54 Number of Teens in Video: 1 Gender of Teens in Video: 1 Female</p> <p>Country: N/A</p>	<p>View Count: 1139 Like Count: 32 Dislike Count: 0 Comments : 10</p>	<p>Pharmacological : N/A</p> <p>Physical Therapy: N/A</p> <p>Psychological Therapy: N/A</p>	<p>N/A</p>	<p>Social Life: People feel like teen is lying because they don't understand.</p> <p>Hard to get out of bed with the pain.</p>
<p>https://www.youtube.com/watch?v=rm8QbAH-DHs</p> <p>Name of Video: Hello Again Search Term: teens with chronic pain Date Posted: November 28th, 2016 Date Retrieved: September 1st, 2017 Length of Video: 12:33 Number of Teens in Video: 1 Gender of Teens in Video: 1 Female</p> <p>Country: United Kingdom</p>	<p>View Count: 50 Like Count: 2 Dislike Count: 0 Comments : 0</p>	<p>Pharmacological : Takes anti-anxiety medications to help with anxiety, but stated that she experienced side effects stating that they were vomiting and sleep deprivation.</p> <p>Physical Therapy: Orthotics</p> <p>Psychological Therapy: Talking with others to overcome dark or suicidal thoughts.</p>	<p>Wears ankle weights but does not say why or who suggested it and for what reason.</p>	<p>Social Life: Made friends with people who also experience chronic pain, felt less judged and more understood.</p> <p>Some friends at school and her family is very supportive. Others don't understand and laugh, that hurts.</p> <p>School/Extracurricular: Had to meet with the school to explain the situation with pain management.</p> <p>No longer possible to dance.</p> <p>Being bullied and laughed at.</p> <p>Physical Education is not as anxious as</p>

		Child and Adolescent Mental Health Services		<p>anticipated.</p> <p>Some school lessons cause pain but pushing through them as she loves the subject and is important for future</p> <p>Can't wear headphones.</p>
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Notes: N/A = not applicable as these heading were not mentioned in the videos.

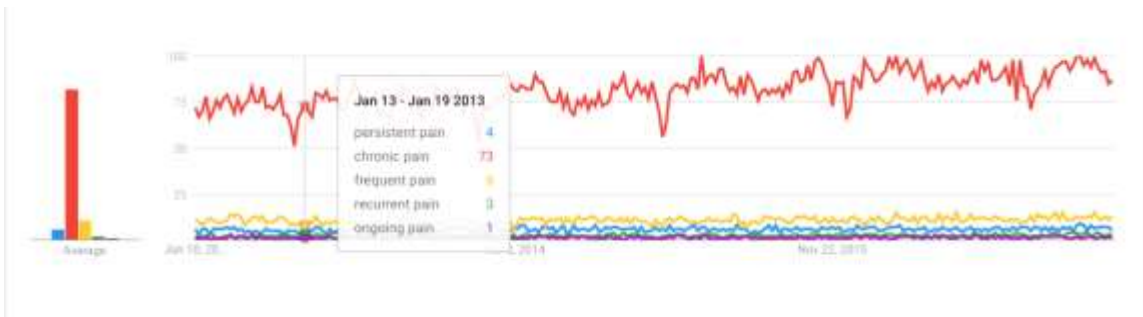


Figure 1

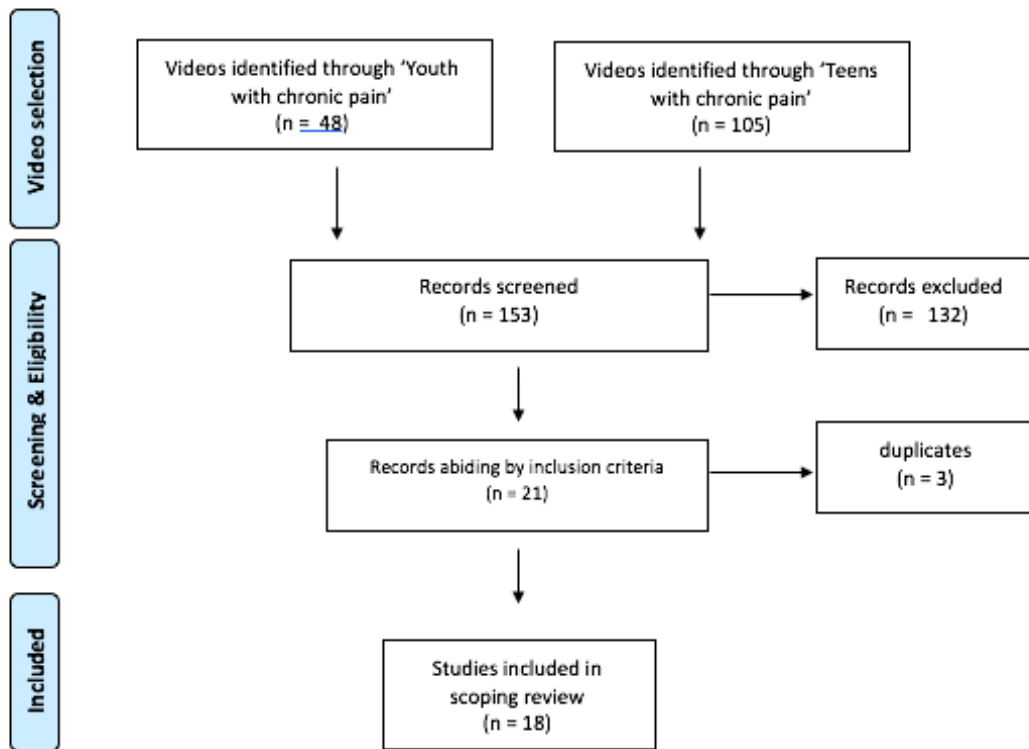


Figure 2