

Social media use in adolescents and young adults with serious illnesses: an integrative review

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Exploring the use of social media by adolescents and young adults with life limiting/threatening conditions: An integrative review

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Exploring the use of social media by adolescents and young adults with life limiting/threatening conditions: An integrative review

Abstract

a. Objectives

Adolescents and young adults with life limiting or life threatening conditions are often socially isolated because of the demands of their illness. Although adolescents and young adults have a noticeable online and social media presence, their motivations for using social media remain unclear. This article aims to summarise empirical research undertaken about how and why social media is used by adolescents and young adults with life limiting or life threatening conditions.

b. Methods

An integrative literature review was undertaken. Key healthcare research databases including CINHAL, MEDLINE, and PSYCHINFO were searched for empirical studies reporting the use of social media by adolescents and young adults with life limiting or life threatening conditions. Fifteen articles met the inclusion criteria; included articles were quality appraised and a thematic synthesis undertaken to identify key themes.

c. Results

The reasons why adolescents and young adults with life limiting or life threatening conditions use social media are diverse, with differences relating to age and gender. However, this population in general uses social media to connect with others who have similar lived experiences.

d. Conclusion

Social media platforms can be useful adjuncts to the care of adolescents and young adults with life limiting or life threatening conditions. However, current evidence is dominated by studies on social media use by adolescents and young adults with cancer. More research is required to gain a holistic understanding of how and why social media is used by this population and its perceived benefits and limitations.

Exploring the use of social media by adolescents and young adults with life limiting/threatening conditions: An integrative review

INTRODUCTION

Adolescents and young adults (AYAs) with life limiting (LLC) or life threatening conditions (LTCs) are a population worthy of inquiry because they reflect the changing palliative care landscape. Developments in medicine and improvements in healthcare has led to AYAs with oncological conditions and neuro-disabilities such as cerebral palsy, neuro-muscular, neuro-metabolic, and genetic disorders living longer (1). Whilst developments and improvements exist relating to medicine, there is a pressing need highlighted within the literature to address and support the psychosocial needs of this population, for example current policy guidance from the National Institute for Health and Care Excellence (2017) on end of life care emphasises the need for emotional and psychological support for young people receiving palliative care.(2) Reports published by UK hospices also identify the importance of supporting the psychosocial needs of AYA's through creating opportunities for AYA's to interact and share experiences with one another.(3) Within care, age-specific psychosocial support is increasingly being acknowledged as a central part of the treatment plan for AYA's with LLCs or LTCs (4). Social media is emerging as a potential avenue for providing psychological and emotional support for AYA's with LLCs or LTCs. However, to our knowledge no review has been undertaken that has summarised empirical research about how and why social media is used by adolescents and young adults with life limiting or life threatening conditions.

Background

AYAs with life limiting conditions (LLCs) or life threatening conditions (LTCs) that are likely to be supported by palliative care services are a unique population. A condition is defined as life limiting when there is no reasonable hope of cure. A condition is life threatening when treatment is feasible, but may fail.(5) Within the UK, the estimated prevalence rate for a young person (under 19) requiring palliative care is sixteen per ten thousand population.(6) From a global perspective, in 2011, over 29 million people died from disease or illness requiring palliative care of which 25% were adolescents.(7) Consequently this group is often underrepresented in terms of ensuring services and care delivery meets their needs. For example, a published report by the Teenage Cancer Trust highlights the issues regarding transition from children's to adult services for this population and the desire for young people to voice their experiences and opinions.(8)

The AYA age group is defined as between the ages of 15 to 39 by the Journal of Adolescent and Young Adult Oncology (AYAJO).(9) However, differences exist in how this population is defined in the United States, Europe and in the UK. For example, in Europe EURO-CARE adopt a more defined 15-24 age bracket. (10) In the UK the Teenage Cancer Trust focuses on a teenage and young adult age group of 13 to 24. (11) Indeed substantial variability exists in how authors define the age group within the literature (12). The changing landscape of palliative care within the UK due to increases in life expectancy as a result of advancements in medicine suggests the AYA age range put forward by the AYAJO may becoming more appropriate. However, it arguably neglects the differences in lived experiences and therefore variance in psychosocial needs within this group. (13). Further research is required to establish how best to define this age group.

Social media is gaining prominence within healthcare with social networking, blogging, media-sharing and virtual reality environments being actively used by both healthcare professionals and patients.(14) Social media is used to aid patient self-expression, facilitate patient and healthcare professional connections, and also provide some individuals an escape from the confinement of a hospital setting.(15,16,17) AYAs worldwide have a strong online and social media presence.(18) For example, in the UK 90% of Instagram users are less than 35 years old and over 65% of Twitter users are under the age of 34.(19) Within healthcare, 95% of adults aged 18 or older with cancer have used or want to use internet sites that offer age appropriate cancer education or support.(20)

The longevity of a LLC or LTC can often result in a gradual intrusion of the illness on the identity of a AYA, to the point where the illness is perceived as an internalised part of the self.(21) Condition characteristics can result

Exploring the use of social media by adolescents and young adults with life limiting/threatening conditions: An integrative review

in bodily changes that impact negatively on body image perceptions.(21) Websites such as JTV Cancer Support aim to remove the isolation that can be caused by the physical and emotional constraints of these illnesses, by allowing AYAs to view, or post videos that discuss issues such as the side effects of LLCs and LTCs and their impacts.(22) Social media can also be used to mitigate the enforced dependency that often comes as a result of a LLC or LTC diagnosis.(23) Dependency can often result in lack of privacy over both physical and emotional boundaries, not least because of the care and support needed from others to enable adherence to treatment regimens or to achieve activities of daily living.(23) Websites that offer spaces for private or communicative blogs such as Tumblr and WordPress can often ameliorate the perceived lack of empowerment, esteem, and independence that can manifest as a result of what can feel like enforced dependency.

A diagnosis of a LLC or LTC can deprive AYAs the opportunity to create diverse and close peer networks. Periods away from educational and social environments, due to illness relapses and undergoing treatments, where networks thrive and friendships are made, often result in AYAs with a LTC or LLC feeling isolated and alone. Such feelings of isolation are confounded by the lack of avenues for confiding with others going through similar experiences.(20) Social media platforms such as Twitter and Facebook are host to a wide range of groups and networks formed by AYAs with LLCs or LTCs, and are actively engaged with by this population. However, their motivations around participation have not been explored.

The evolving and adaptive nature of social media means a comprehensive review of the grey literature would be unmanageable. However, in order to gain a broad understanding of the current position and weight of empirical literature on how and why social media is used by AYAs with LLCs or LTCs, an integrative review was undertaken.

THE REVIEW

Aim

This integrative review aims to summarise empirical research indicating how and why social media is used by AYAs with LLCs or LTCs.

Design

The integrative review was underpinned by a 6 stage process that briefly involved; problem identification whereby the review purpose is established; a well-defined literature search; evaluation of the data where articles are assessed for quality; data analysis (where the data is ordered and compared allowing themes and patterns to arise); and finally presentation of findings.(24) Integrative reviews in comparison to other more traditional review methods such as systematic reviews, allow for the inclusion of both experimental and non-experimental research as oppose to placing emphasis on randomised clinical trials and quantitative studies.(25) Therefore, an integrative review was the most appropriate review method to summarise empirical research indicating how and why social media is used by AYAs with LLCs or LTCs.

Search Methods

Selection criteria were identified in advance of the review and included the following criteria; the sample included adolescents and young adults aged 15 to 39 years with life limiting or life threatening condition, the focus on the study was on social media use. Studies were published after 1989 in line with the birth of the internet. Studies were published in the English Language. Databases outlined in the PRISMA diagram (figure 1) were searched in March 2017 and an updated search in August 2018 did not retrieve any additional studies. In order to identify suitable studies, the databases outlined in the PRISMA diagram (Figure 1) were searched. With the support of an information specialist, a relevant and comprehensive search strategy was developed based on the research questions and key concepts. The search syntax was composed of three key words and their synonyms: 1) 'Teenagers' with examples of synonyms being 'young adult', 'young person', 'adolescent' as well as the different types of spelling (UK and US); 2) 'Life-limiting conditions' with examples of synonyms being 'life threatening conditions', 'palliative care' and 'end-of-life care' ; 3rd) 'Social media' with examples of synonyms being 'internet', 'peer to peer interaction' and 'Twitter'. Given the potential variances in definitions for terms such as 'social media', 'life limiting condition', 'life threatening condition', and 'adolescent and

Exploring the use of social media by adolescents and young adults with life limiting/threatening conditions: An integrative review

young adult’, key terms were defined prior to the search in order to set the parameters of the search to ensure consistency as outlined below:

Social Media is an ever evolving and adapting phenomena. However, this review adopts the following definition of social media as: internet-based tools that facilitate communication between individuals and communities, to disseminate information, ideas, messages, images, and other content, and often collaborate with other users in real time.(14)

Adolescents and Young Adults (AYA) are defined in the current review as individuals aged fifteen to thirty nine (9). The relative anonymity that social media facilitates results in studies within this inquiry often having vague and broadly defined age ranges. As such, a more defined age range may have limited the results of the literature search. Therefore the authors adopted the AYA definition to facilitate the inclusion of studies that represent the current breadth of literature.

Life Limiting Condition is defined by Together for Shorter Lives (2017) as those conditions for which there is” no reasonable hope of cure and from which children and young people will die”.(5)

Life Threatening Condition is defined by Together for Shorter Lives (2017) as a condition “for which curative treatment may be feasible but can fail, such as cancer”.(5)

To manage the digital output from the search, EndNote and Covidence software were used. EndNote allowed for the storage of the references and management of citations. Covidence was used for the process of study selection. In total 2696 references were generated through this process with the majority sourced through online databases (Figure 1).

Search Outcome

Details of the study identification and selection process are shown in the PRISMA flowchart (Figure 1). The initial search of electronic databases yielded 2696 references which were imported into the online software Covidence in preparation for title and abstract by GP with uncertainties discussed with AR and JS. Ninety five articles were retrieved for full text screening conducted by three reviewers (GP, AR, JS) of which 11 met the selection criteria. A further 9 articles were retrieved and screened for eligibility. Four of the articles met the selection criteria. In total 15 articles satisfied the inclusion criteria and were included in the review (Table 1).

Table 1. Article matrix table

Author/s	Study Aim	Methods	Sample	Key Findings
Bers MU, Gonzalez-Heydrich J, Raches D, et al.(2001) USA	To trial a piece of interactive software (Zora) in a paediatric dialysis unit to explore if Zora aids self-understanding of illness	Ethnographic approach aimed at gathering data to represent a rich description of how Zora was used.	Sample Characteristics 4 females, 4 males with end stage renal disease	Zora was used to escape as oppose to confront illness. Young people consciously avoided any mentioning of their condition on Zora.
			Sample Age Mean age 15.4 years	
Crook B, Glowacki ME, Love B, et al. (2015) USA	To examine how the use of discourse, pronouns, tense, and verbs impacts the extent to which an online post receives a response.	Quantitative analysis using linguistic inquiry word count software	Sample Characteristics Young adults with cancer	Posts without replies included more words per sentence. Posts with replies included more words that express negative emotion, anxiety, and anger
			Sample Age Young adults, age range undefined.	

Exploring the use of social media by adolescents and young adults with life limiting/threatening conditions: An integrative review

Crook B, Love B. (2016) USA	To explore the challenges that young people face when participating in an online young person's cancer support forum.	Qualitative analysis of content posted on an online support forum	Sample Characteristics Young adults with cancer	Young adults express concern about the accuracy of information shared online.
			Sample Age Young adults, age range undefined	Response from posts can often increase anxiety as oppose to alleviating it.
Donovan EE, LeFebvre L, Tardiff S, <i>et al.</i> (2014) USA	To understand the social support young adults with cancer receive on an online discussion group.	Mixed methods analysis of 510 responses to posts in an online discussion group.	Sample Characteristics Adolescents and young adults with cancer	Informational support was present in 82% of replies. Respondents offered own experiences as a way of providing uncertainty management.
			Sample Age Adolescents and young adults, age range undefined.	
Griffiths C, Panteli N, Brunton D, <i>et al</i> (2015) U.K.	To design the Realshare website based on young people's input and preferences. To determine the acceptability of Realshare among young adults with cancer.	Participatory design aimed at empowering young people with cancer to design and use a website. Qualitative interviews to understand the acceptability of Realshare among young adults with cancer.	Sample Characteristics 7 females 5 males who previously or currently have cancer.	By engaging young people with cancer in the designing and evaluating of Realshare, the website was tailored to the needs of the population and therefore increased the likelihood of its use. Young people encouraged and welcomed adult facilitator involvement on the website.
			Sample Age Between 16 and 30 years. Mean age. 21.08 years	
Keim-Malpass J, Adelstein K, Kavalieratos D. (2015) USA	To explore the blogs of five women with advanced cancer who all passed away to explore key elements of legacy making and grief processing.	Qualitative narrative analysis of online illness blogs.	Sample Characteristics 5 women who had advanced cancer	Blogs facilitate legacy making by offering young women with cancer a unique opportunity to be remembered through the public sharing of words, pictures, and life experiences
			Sample Age 25-39 years	
Keim-Malpass J, Albrecht T, Steeves R H, <i>et al.</i> (2013) USA	To explore the narratives shared by young women online with cancer.	Qualitative analysis of 16 online illness blogs	Sample Characteristics 16 women with cancer	Sensitive issues such as fertility, and financial difficulties were the main themes that arose from the data suggesting women found blogging to be a safe space where they could divulge and discuss sensitive topics.
			Sample Age 20-39 years	

Exploring the use of social media by adolescents and young adults with life limiting/threatening conditions: An integrative review

Keim-Malpass J, Steeves HR (2012) USA	To explore the experiences of young women with cancer through an analysis of their illness blogs.	Qualitative thematic analysis of online blogs with a focus on participant's lived experience.	Sample Characteristics 16 women with cancer	Blogs provided an online space for women to express themselves. All participants used their blogs extensively, and as such were able to reveal their whole narrative.
			Sample Age 20-39 years	
Love B, Thompson CM, Knapp J (2014) USA	To investigate how gender specific issues shape the experiences of young adult men with cancer and what they report to be problematic.	Qualitative analysis of content of online forums Focus groups with 6 men Individual interviews with 4 men	Sample Characteristics Young men affected by cancer.	Young men have a desire to be emotionally expressive online Appropriate emotional support is severely hindered by cultural expectations of masculinity. The pressure to be strong is an overarching barrier that prevents young men receiving or offering emotional support.
			Sample Age Online forum: 18-39 years Focus group: Mean age 28 Individual interviews: Mean age: 31.	
Lowney AC, O'Brien T (2012) Ireland	A case study of a 30 year old male receiving palliative care who maintained an illness blog.	Qualitative case study	Sample Characteristics Young male with cancer receiving palliative care	Blogging facilitates legacy making and allows for experiences and narratives to be shared and preserved online.
			Sample Age 30 years old.	
Myrick JG, Holton AE, Himelboim I, <i>et al.</i> (2016) USA	To investigate which forms of social support will be the most common on a twitter-based cancer community.	A quantitative analysis of tweets containing #stupid cancer over a period of two years.	Sample Characteristics Young adults impacted by cancer	64.7% of tweets contained informational support whilst only 12% contained emotionally expressive content.
			Sample Age Young adults, age range undefined	
Nesby L, Salamonsen A (2016) Norway	To explore the blogs of two young women who had life limiting conditions.	Qualitative analysis of the posts from two illness blogs	Sample Characteristics Two young women who died of cancer	Blogging allowed the women to maintain a presence online. Both women felt empowered through blogging.
			Sample Age Age 15 and Age 17	
Pounders K, Stowers K (2017) USA	To better understand gender and identity issues among young females with cancer	Qualitative analysis of posts on a discussion board.	Sample Characteristics Adolescents and young adults with cancer	Women posted content relating to gender and identity such as issues relating to motherhood, physical attractiveness, and romantic relationships.
			Sample Age AYAs defined as 15-39 years	

Exploring the use of social media by adolescents and young adults with life limiting/threatening conditions: An integrative review

Thompson CM, Crook B, Love B <i>et al</i> (2016) USA	To explore why adolescents and young adults might choose to seek support in either a face to face or online scenario.	Transcripts from an online discussion board and face-to-face support group analysed using linguistic inquiry and word count computer based software.	Sample Characteristics Adolescents and young adults with cancer	Discussions relating to sex were more prominent on the online group compared to the face to face group.
			Sample Age AYAs defined as 15-39 years	Ratios of emotive words were higher online.
Winterling J, Wiklander M, Obol C, <i>et al.</i> (2016) Sweden	Developing an interactive website designed to support young cancer patients with sexual problems and fertility distress.	Participatory research with young adults contributing to developing an interactive website. Design included qualitative interviews, analysed	Sample Characteristics 11 AYAs who had undergone treatment for any cancer. 2 mothers of teenagers who had undergone treatment for cancer	Participant involvement impacted on the quality of website content and relevance to potential users. Motivation to participate was to share experiences and support others in a similar situation
			Sample Age 16-40	

Quality Appraisal

All 15 articles were published in peer review journals and thus met the minimum quality criteria. Given the inclusion of qualitative, quantitative, and mixed method studies it was appropriate to use the Mixed Methods Appraisal Tool (MMAT).(26) The tool provides criteria to appraise the methods of qualitative, quantitative, and mixed method research designs. Findings from the quality appraisal are presented in Table 2, studies all scored about 75%, therefore were all included in the review. Study limitations relating to application of methods are addressed in the discussion.

Table 2. Mixed methods appraisal tool.

Reference (Author, year)	Methodological quality criteria - QUALITATIVE DESIGNS				Overall score
	Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objectives)?	Is the process for analysing qualitative data relevant to address the research question (objective)?	Is appropriate consideration given to how findings relate to the context, e.g. the setting in which the data was collected?	Is appropriate consideration given to how findings relate to researcher's influence, e.g. through their interactions with participants?	
Bers et al (2001)	1	1	1	1	100%
Crook and Love (2016)	1	1	1	0	75%
Griffiths <i>et al</i> (2015)	1	1	1	0	75%

Exploring the use of social media by adolescents and young adults with life limiting/threatening conditions: An integrative review

Keim-Malpass and Steeves (2012)	1	1	1	1	100%
Keim-Malpass et al (2013)	1	1	1	1	100%
Keim-Malpass et al (2015)	1	1	1	0	75%
Love et al (2014)	1	1	1	0	75%
Lowney and O'Brien (2012)	1	1	1	0	75%
Nesby and Salamonsen (2016)	1	1	1	0	75%
Pounders et al (2017)	1	1	1	0	75%
Winterling <i>et al</i> (2016)	1	1	1	0	75%
Methodological quality criteria - QUANTITATIVE DESIGNS					
	Is the sampling strategy relevant to address the quantitative research strategy?	Is the sample representative of the population understudy?	Are measurements appropriate (clear origin, or validity known, or standard instrument)?	Is there an acceptable response rate (60% or above)?	
Crook et al (2015)	1	1	1	0	75%
Myrick et al (2016)	1	1	1	0	75%
Thompson et al (2016)	1	1	1	0	75%
Methodological quality criteria - MIXED METHODS DESIGNS					
	Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (objective)?	Is the integration of qualitative and quantitative data (or results) relevant to address the research question (objective)?	Is appropriate consideration given to the limitations associated with this integration, e.g. divergence of qualitative and quantitative data (or results)?		
Donovan et al (2014)	1	1	1	1	100%
Qualitative criteria	Are the sources of qualitative data (archives, documents, informants, observations)	Is the process for analysing qualitative data relevant to address	Is appropriate consideration given to how findings relate to the		

Exploring the use of social media by adolescents and young adults with life limiting/threatening conditions: An integrative review

	relevant to address the research question (objectives)?	the research question (objective)?	context, e.g. the setting in which the data was collected?	
Donovan et al (2014)	1	0	1	75%
Quantitative criteria	Is the sampling strategy relevant to address the quantitative research strategy?	Is the sample representative of the population understudy?	Are measurements appropriate (clear origin, or validity known, or standard instrument)?	
Donovan et al (2014)	1	1	0	75%
Scoring metrics key 1 = Yes 0 = No or Can't Tell. <i>The score is 25% when QUAL=1 or QUAN=1 or MM=0, it is 50% when QUAL =2 or QUAN=2 or MM=1, it is 75% when QUAL=3 or QUAN=3 or MM=2, and it is 100% when QUAL=4 and QUAN=4 and MM=3.</i> <i>QUAL= Qualitative QUAN= Quantitative and MM= Mixed Methods (26)</i>				

Data abstraction and synthesis

A thematic synthesis of the articles that met the inclusion criteria was undertaken. Included papers were read by authors GP, AR, and JS and were individually coded. Codes from each article were then summarised and recorded on a data extraction form (Table 1) that assisted the authors in identifying patterns across studies. Codes that were prevalent across studies were then grouped into broad themes. An iterative process of moving between the broad themes and individual codes took place until a coherent account of the literature reviewed emerged.

RESULTS

Description of the studies

Eleven of the 15 studies included were published in the USA, with the other 4 studies published in Sweden, Ireland, Norway, and England (Table 1). Articles were published between the years of 2001 to 2017 with the majority published either in 2015 or 2016 (Table 1). Methodological approaches varied, however the majority of studies (n=11) were qualitative in design and most commonly used a thematic analysis of online data. Other qualitative approaches included participatory design and ethnography.(27,28,17) Three studies were quantitative focusing on the prevalence of related discourse and word count on social media sites and discussion forums.(29,30,31) One study adopted a mixed method approach exploring the prevalence of topics online(32).

A comparison of articles revealed three prominent themes: Influences in platform choice and content shared, reasons for social media use by AYAs with LLCs or LTCs and barriers to using social media.

THEME 1. Influences in platform choice and content shared.

Eight articles (Table 1) highlighted that the reasons why AYAs use social media impacts the type of social media content shared and the platform used to share the content. (15, 30, 31, 32, 33, 34, 35, 36).

AYAs who share personal and emotive content relating to their condition tended to use blogging sites (15, 33, 34, 35, 36). By contrast, more informative content such as threads relating to treatment plans appear on discussion boards and forums (30, 32). Whilst instances of emotive content featuring on discussion boards does exist, it is dependent upon an intercommunicative relationship between poster and responder.(31) By comparison, blogging can be used solely for the purpose of private individual self-expression and therapy

Exploring the use of social media by adolescents and young adults with life limiting/threatening conditions: An integrative review

without the need for intercommunication. However, intercommunication between AYAs engaging with blogs that are open does have benefits such as facilitating a supportive online space for AYAs.(15, 33, 34)

Gender appears to influence the type of content shared and platforms used to share content. Analysis of studies with a female sample found social media was used to share deeply emotive content about sensitive issues such as fertility.(33,36,37) In addition, social media appears to be perceived as an escape for AYA women where they could express emotive narrative concerning topics with which they often did not want their friends and families to know about for fear of upsetting them.(34) By contrast, studies with a male population featured social media content that was more reserved and confronted sensitive topics with humour as opposed to compassion and empathy.(38) Barriers surrounding expectations and beliefs surrounding masculine identity such as the need to show strength as a possible reason as to why men are apparently more reserved on social media.(38)

THEME 2. Reasons for social media use by adolescents and young adults with life limiting/threatening conditions.

Across studies reviewed a common theme was that AYAs with LLCs or LTCs use social media to interact with others with similar lived experiences, to feel empowered, and to share their illness narrative. Studies that support this theme are highlighted within each of the sub themes.

2.1. To interact with others with similar lived experiences.

The ability to interact with others with similar lived experiences through interactive websites, discussion boards, and blogging appears to be a key motivator for using social media. Nine articles supported this sub theme (Table 1).(15, 31, 32, 33, 34, 36, 37, 37) AYAs with LLCs or LTCs appear more comfortable discussing issues of sensitivity such as concerns over fertility or financial issues with peers online going through similar experiences.(15) Similarly, the ability to stay relatively anonymous can facilitate AYAs to express emotions, feelings, and experiences in relation to gender, sexuality, and identity, that they may not share with well peers and family(31,37)

2.2. Agency/Empowerment.

Social media can empower AYAs with LLCs or LTCs to seek emotional and informational support from others online. Four articles supported this sub theme (Table 1). (31, 33, 36, 37) The ability to detail their narrative through social media and share it with others via blogging can also be an empowering experience for AYAs.(33,35) More so, instances of health professionals contributing to content posted online by AYAs with LLCs or LTCs are becoming more common and suggests a change in the patient health professional relationship.(27)

2.3. To share their illness narrative.

The ability to share and portray their illness narrative in a way that is meaningful to the individual is a reason why some AYAs with LLCs or LTCs use social media. Three articles support this sub theme.(15, 35, 36) Blogging appears to be the most common way that AYAs engage in this reflective and sense making activity. Reasons for chronicling their illness narrative via blogging appears to be related to the therapeutic benefits related to the practice and a desire to leave a legacy. Some AYAs with LLCs or LTCs found sharing their illness narrative to be therapeutically beneficial in that it provided a space to make sense of aspects of their illness journey in real time. In addition, the relative anonymity of blogging provides a platform for AYAs to voice existential distress. The desire to be remembered and to leave a legacy appears to be attributed to AYAs with LLCs or LTCs sharing their illness narrative.

THEME 3. Barriers to using social media.

Barriers to using social media relate to the accuracy of content, negative responses to content, and fear of nonresponse to posts. Three articles supported this theme (Table 1). (29, 36, 39) Studies included in the review highlight some of the barriers and reservations AYAs with LLCs or LTCs have about using social media. Concerns about the accuracy of information shared on online forums and discussion boards were evident.(29). In addition, whilst the majority of support received online appears to be positive, AYAs with LLCs or LTCs are

Exploring the use of social media by adolescents and young adults with life limiting/threatening conditions: An integrative review

also exposed to negative comments that can often be distressing.(36) The intercommunicative dependence of discussion boards and forums can at times lead to posters not receiving a response to their post and as such result lead to feelings of isolation.(39)

DISCUSSION

The findings of the review offer an insight into how and why AYAs with LLCs or LTCs use social media. The review found that for AYAs with LLCs or LTCs who have a desire to engage with online communities, those communities established across various platforms are unified in their aim to provide or receive support from others with similar lived experiences to themselves. This support includes offering informational support, emotional support, or participatory engagement in the design of interactive websites built with the aim of helping others.(15,27,32) The wider literature suggests that AYAs with long-term conditions have differing experiences of using social media. For example, one study found that young people with long-term did not disclose their health information or status to others and instead opted to use social media as a place to be a 'regular' as opposed to ill teenager.(40) Similarly, a further study highlights how AYAs with long term conditions use social media to stay connected with family and friends as opposed to interacting with illness specific discussion boards and forums.(41)

Whilst the majority of studies reviewed focused on blogs or discussion boards/forums and therefore determined the trend of findings discussed, two studies focused on online support programs and presented findings that suggest the future direction for online support for AYAs with LLCs or LTCs. Both studies highlighted a desire for online support programs that encompass both a space to discuss and receive support from peers, and a space to discuss and receive support from health care professionals.(27,28) A move towards online websites that integrates both health care professional informational support and social and peer emotional support is also supported within the literature.(41)

Limitations of articles included in the review

Articles underwent study appraisal using a mixed methods analysis framework with all articles meeting the quality criteria.(26) Nonetheless, limitations exist within the studies reviewed. Study appraisal highlighted the lack of reflexive processes adopted by authors in relation to the 11 qualitative articles reviewed (Table 2). Reflexivity is an essential stage, or at the very least acknowledgement of a qualitative research methodology when considering the possible role author assumptions and beliefs may have had on the analysis of data. In relation to the data collected, there is an evident lack of data gathered through face to face data collection methods such as interviews or focus groups with majority of studies analysing online data. Whilst online data provides a clear insight into the content expressed by AYAs with LLCs or LTCs, it is limited in its capability to understand the motivation and circumstances around the content published.

The AYA age range of 15-39 years featured within 11 of the studies reviewed, with the remaining 4 studies offering a more defined sample age. Findings from these studies tended to offer greater insights into the different psychosocial needs of AYAs. For example, one study with a mean age of 15 highlighted that through gamification participants used the platform to escape their illness, engaging in activity that allowed them to express their hobbies and interests to others (17). By contrast, a study that analysed content on a discussion board found AYAs with a mean age of 30 posted emotive and expressive content detailing their struggles with illness. (33) Concerns around the generalisability and perceived homogeneity of the AYA age range are prevalent within the literature (13). A proposed alternative approach to defining the sample is to subdivide it into three categories (15-18, 19-24, 25- 39) in order to better capture the different physiological and psychosocial realities experienced by AYAs.(12) This approach could be useful in delivering appropriate online psychosocial support. However, as the review has highlighted the relative anonymity of social media may make its application challenging within this area of inquiry.

Limitations in study samples were also evident in relation to the type of LLC or LTC AYAs recruited, or observed for study had. Of the 15 articles reviewed, 14 studies had a sample of AYAs-with a cancer related condition with end stage renal disease being the only other representation of LLCs or LTCs despite a

Exploring the use of social media by adolescents and young adults with life limiting/threatening conditions: An integrative review

comprehensive search of multiple databases (Figure 1)(7). As of 2013, there are over 300 conditions that are defined as life limiting or life threatening affecting AYAs, all with diverse illness trajectories and symptom management.(42) The dominance of oncology related studies within this review offers a strong indication of the current position, direction and breadth of literature in this area. Furthermore, the requirement for further research into other LLCs or LTCs is stark and essential if the field is to reach a comprehensive understanding of social media use by AYAs with LLCs or LTCs.

Limitations of the review

There are limitations to this review relating to the search methods used to identify articles. Authors searched a variety of health related electronic databases (figure 1) to identify articles. Inconsistencies in search terminology and indexing problems can result in studies being unidentified through this search method strategy (24). In order to reduce inconsistencies in search terminology the authors developed the search strategy with the aid of an information specialist. In addition, manual searches of identified article reference lists were undertaken to identify articles (figure 1). It is also acknowledged by the authors that valuable research within this field may exist from non-empirical sources based within the grey literature. However, to attempt to capture such sources would have been unmanageable due to the ever evolving and expanding nature of social media.

Implications for healthcare provision

This review has highlighted that for many AYAs with LLCs or LTCs much of their health care narrative exists online. As such, health care professionals can gain valuable insights into the patient journeys and lived experiences through the vast and ever developing array of websites, forums, discussion boards, blogs and additional health related social media content that exists. The diversity of social media platforms for different purposes further demonstrate the variability and therefore potential capacity of social media to aid the psychosocial wellbeing of AYAs with LLCs or LTCs.

CONCLUSION

This review identifies that AYAs with LLCs or LTCs use social media to predominantly connect with others who have similar lived experiences. Differences exist in how they choose to connect in terms of the content shared and the varying types of social media used. The review highlights evident gaps within the literature with the majority of studies reviewed focusing upon AYAs with cancer as oppose to those with other life limiting or life threatening conditions. Furthermore, the study design of the majority of studies reviewed is focused upon the analysis of online data. As such, there is a paucity of in depth studies that look to understand the motivations and circumstances that lead AYAs with LLCs or LTCs to use social media and post such content. This review confirms that in order to fully understand the potential of social media to provide support to AYAs with LLCs or LTCs, further research is needed that incorporates a more diverse range of samples and methodologies.

Exploring the use of social media by adolescents and young adults with life limiting/threatening conditions: An integrative review

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