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

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ABSTRACT

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.

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.

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.

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.

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 neuromotor disabilities such as cerebral palsy, neuromuscular, neurometabolic and genetic disorders living longer. While 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 on end of life care emphasises the need for emotional and psychological support for young people receiving palliative care. Reports published by UK hospices also identify the importance of supporting the psychosocial needs of AYAs through creating opportunities for AYAs to interact and share experiences with one another. 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. Social media is emerging as a potential avenue for providing psychological and emotional support for AYAs 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 AYAs with LLCs or LTCs.

Background

AYAs with LLCs or 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. Within the UK, the estimated prevalence rate for a young person (under 19) requiring palliative care is 16 per 10 000 population. From a global perspective, in 2011, over 29
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. 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 six-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. 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. 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 AYAs aged 15 to 39 years with LLC or LTC,
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 Preferred Reporting Items for Systematic Reviews and Meta-Analyses (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 USA); (2) ‘Life-limiting conditions’ with examples of synonyms being ‘life threatening conditions’, ‘palliative care’ and ‘end-of-life care’; and (3) ‘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 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 are defined in the current review as individuals aged 15 to 39.9 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 Lives5 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 Lives5 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 screening 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 nine 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).

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.25 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.

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 and 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.17 26 27 Three studies were quantitative focusing on the prevalence of related discourse and word count on social media sites and discussion forums.28–30 One study adopted a mixed method approach exploring the prevalence of topics online.31

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 29–34

AYAs who share personal and emotive content relating to their condition tended to use blogging
## Table 1: Article matrix table

| Author/s                  | Study aim                                                                 | Methods                                                                 | Sample Characteristics                                                                 | Key findings                                                                                           |
|---------------------------|---------------------------------------------------------------------------|-------------------------------------------------------------------------|------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------|
| Bers 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. Sample age: mean age 15.4 years. | Zora was used to escape as an oppose to confront illness. Young people consciously avoided any mentioning of their condition on Zora. |
| Crook et al (2015) USA    | To examine how the use of discourse, pronouns, tense and verb count impacts the extent to which an online post receives a response. | Quantitative analysis of linguistic inquiry word count software.       | Sample characteristics: Young adults with cancer. Sample age: Young adults, age range undefined. | Posts without replies included more words per sentence. Posts with replies included more words that express negative emotion, anxiety and anger. |
| Crook and Love (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. Sample age: Young adults, age range undefined. | Young adults express concern about the accuracy of information shared online. Response from posts can often increase anxiety as oppose to alleviating it. |
| Donovan et al (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. Sample age: Adolescents and young adults, age range undefined. | Informational support was present in 82% of replies. Respondents offered own experiences as a way of providing uncertainty management. |
| Griffiths et al (2015) UK | 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. Sample age: Between 16 and 30 years. Mean age: 21.08 years. | 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. |
| Reim-Malpass et al (2015) USA | To explore the blogs of 5 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. Sample age: 25–39 years. | 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. |
| Reim-Malpass et al (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. Sample age: 20–39 years. | 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. |
| Reim-Malpass (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 participants’ lived experience. | Sample characteristics: 16 women with cancer. Sample age: 20–39 years. | 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. |
| Love et al (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. Sample age: Online forum: 18–39 years. Focus group: mean age 28. Individual interviews: mean age 31. | 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. |
| Lawton et al (2012) Ireland | A case study of a 30-year-old man receiving palliative care who maintained an illness blog. | Qualitative case study.                                               | Sample characteristics: Young male with cancer receiving palliative care. Sample age: 30 years old. | Blogging facilitates legacy making and allows for experiences and narratives to be shared and preserved online. |
| Myrick et al (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 2 years. | Sample characteristics: Young adults with cancer. Sample age: Young adults, age range undefined. | 64.7% of tweets contained informational support while only 12% contained emotionally expressive content. |
### Table 1

| Authors | Study aim | Methods | Sample characteristics | Sample age | Sample characteristics | Sample age |
|---------|-----------|---------|------------------------|------------|------------------------|------------|
| Nesby and Salamonsen34 (2016) Norway | To explore the blogs of two young women who had life-limiting conditions. | Qualitative analysis of the posts from two illness blogs. | Two young women who died of cancer. | Age 15 and age 17. | Blogging allowed the women to maintain a presence online. | Both women felt empowered through blogging. |
| Pounders et al35 (2017) USA | To better understand gender and identity issues among young females with cancer. | Qualitative analysis of posts on a discussion board. | Adolescents and young adults with cancer. | AYAs defined as 15–39 years. | Women posted content relating to gender and identity such as issues relating to motherhood, physical attractiveness and romantic relationships. | |
| Thompson et al30 (2016) USA | To explore why adolescents and young adults with cancer 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. | Adolescents and young adults with cancer. | AYAs defined as 15–39 years. | Discussions relating to sex were more prominent on the online group compared with the face-to-face group. | Ratios of emotive words were higher online. |
| Winterling et al27 (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. | 11 AYAs who had undergone treatment for any cancer. | AYAs defined as 15–39 years. | Participant involvement impacted on the quality of website content and relevance to potential users. | Motivation to participate was to share experiences and support others. |

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By contrast, more informative content such as threads relating to treatment plans appear on discussion boards and forums. While instances of emotive content featuring on discussion boards does exist, it is dependent on an intercommunicative relationship between poster and responder. By comparison, blogging can be used solely for the purpose of private individual self-expression and therapy 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.

Gender appeared 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. In addition, social media appeared 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. 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. Barriers related to expectations and beliefs surrounding masculine identity such as the need to show strength is a possible reason why men are apparently more reserved on social media.

### Theme 2. Reasons for social media use by AYAs with LLCs/LTCs

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 supported this theme are highlighted within each of the sub themes.

#### 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 appeared to be a key motivator for using social media. Nine articles supported this sub theme (table 1). AYAs with LLCs or LTCs appeared more comfortable discussing issues of sensitivity such as concerns over fertility or financial issues with peers online going through similar experiences. 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.

#### 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). The ability to detail their narrative through social media and share it with others...
| Reference (author, year) | 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, for example, the setting in which the data was collected? | Is appropriate consideration given to how findings relate to researcher’s influence, for example, through their interactions with participants? | Overall score |
|-------------------------|--------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------|--------------------------------------------------------------------------------|----------------|
| Bers et al* (2001)      | 1                                                                                                                                  | 1                                                                                           | 1                                                                                | 1                                                                                | 100%           |
| Cook and Love* (2016)  | 1                                                                                                                                  | 1                                                                                           | 1                                                                                | 0                                                                                | 75%            |
| Griffiths et al* (2015) | 1                                                                                                                                  | 1                                                                                           | 1                                                                                | 0                                                                                | 75%            |
| Neim-Malpass et al* (2012) | 1                                                                                                                                  | 1                                                                                           | 1                                                                                | 1                                                                                | 100%           |
| Neim-Malpass et al* (2013) | 1                                                                                                                                  | 1                                                                                           | 1                                                                                | 1                                                                                | 100%           |
| Neim-Malpass et al* (2015) | 1                                                                                                                                  | 1                                                                                           | 1                                                                                | 0                                                                                | 75%            |
| Love et al* (2014)      | 1                                                                                                                                  | 1                                                                                           | 1                                                                                | 0                                                                                | 75%            |
| Lovney and O’Brien* (2012) | 1                                                                                                                                  | 1                                                                                           | 1                                                                                | 0                                                                                | 75%            |
| Nesby and Salamonson* (2016) | 1                                                                                                                                  | 1                                                                                           | 1                                                                                | 0                                                                                | 75%            |
| Pounders et al* (2017)  | 1                                                                                                                                  | 1                                                                                           | 1                                                                                | 0                                                                                | 75%            |
| Winterling et al* (2016) | 1                                                                                                                                  | 1                                                                                           | 1                                                                                | 0                                                                                | 75%            |

Methodological quality criteria—quantitative designs

| Reference (author, year) | 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)? | Overall score |
|-------------------------|--------------------------------------------------------------------------------|-----------------------------------------------------------|-------------------------------------------------------------------------------------|-----------------------------------------------------|----------------|
| 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

| Reference (author, year) | 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 the integration of qualitative and quantitative data (or results) relevant to address the research question (objective)? | Is appropriate consideration given to how findings relate to the context, for example, the setting in which the data were collected? | Is appropriate consideration given to how findings relate to researcher’s influence, for example, through their interactions with participants? | Overall score |
|-------------------------|--------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------|--------------------------------------------------------------------------------|--------------------------------------------------------------------------------|----------------|
| Donovan et al* (2014)   | 1                                                                              | 1                                                          | 1                                                                                  | 1                                                                                | 100%                                                                       | 100%          |
| Qualitative criteria    | 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 the integration of qualitative and quantitative data (or results) relevant to address the research question (objective)? | Is appropriate consideration given to how findings relate to the context, for example, the setting in which the data were collected? | Is appropriate consideration given to how findings relate to researcher’s influence, for example, through their interactions with participants? | 100%          |
| Donovan et al* (2014)   | 1                                                                              | 0                                                          | 1                                                                                  | 1                                                                                | 75%                                                                       | No            |
| 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)? | Is there an acceptable response rate (60% or above)? | 75% | No |

Donovan et al* (2014) | 1 | 0 | 1 | 75% | No |

Donovan et al* (2014) | 1 | 1 | 0 | 75% | Can’t tell |

Scoring metrics key.
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.
1 = Yes 0 = No or Can’t Tell
QUAL, Qualitative; QUAN, Quantitative; MM, Mixed Methods (26).
via blogging can also be an empowering experience for AYAs. 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.

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 supported this sub theme. Blogging appeared to be the most common way that AYAs engage in this reflective and sense-making activity. 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 online.

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 non-response to posts. Three articles supported this theme (table 1). Studies included in the review highlighted some of the barriers and reservations AYAs with LLCs or LTCs have about using social media.

Concerns about the accuracy of information shared online forums and discussion boards were evident. In addition, while the majority of support received online appears to be positive, AYAs with LLCs or LTCs are also exposed to negative comments that can often be distressing. 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.

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. 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 conditions 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. Similarly, a further study highlighted how AYAs with long-term conditions used social media to stay connected with family and friends as opposed to interacting with illness-specific discussion boards and forums.

While 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 programmes 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 programmes that encompass both a space to discuss and receive support from peers, and a space to discuss and receive support from healthcare professionals. A move towards online websites that integrates both healthcare professional informational support and social and peer emotional support is also supported within the literature.

Limitations of articles included in the review
Articles underwent study appraisal using a mixed methods analysis framework with all articles meeting the quality criteria. 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. While online data provided 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.

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. Concerns around the generalisability and perceived homogeneity of the AYA age range are prevalent within the literature. A proposed alternative approach to defining the sample is to subdivide it into three categories (15-18 yrs, 19-24yrs, 25-39yrs) in order to better capture the different physiological
and psychosocial realities experienced by AYAs.\textsuperscript{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 comprehensive search of multiple databases (figure 1).\textsuperscript{7} As of 2013, there are over 300 conditions that are defined as LLC or LTC affecting AYAs, all with diverse illness trajectories and symptom management.\textsuperscript{40} 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.\textsuperscript{23} 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 healthcare narrative exists online. As such, healthcare 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 well-being 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 on AYAs with cancer as oppose to those with other LLCs or LTCs. Furthermore, the study design of the majority of studies reviewed is focused on 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.

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