

## Original Article

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# Evaluating a novel hospital-based online health community to address palliative and psychosocial care factors for chronically ill adolescent and young adult patients

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**Abstract**

**Objectives.** Chronically ill adolescent and young adult (AYA) patients experience barriers to accessing psychosocial care. AYAs who receive palliative and psychosocial care experience numerous benefits from these services. However, we still lack research investigating age-appropriate programs targeting AYAs' psychosocial needs that are delivered virtually and extend beyond the hospital setting. *Streetlight* is a palliative care program designed for chronically ill AYAs that offers the *Streetlight Gaming League (SGL)*, an online health community (OHC) combining peer-based support, online gaming, and community events. We evaluated the usefulness, acceptability, and potential effectiveness of *SGL* through an assessment of chronically ill AYAs' lived experiences.

**Methods.** We used a qualitative evaluation approach grounded in hermeneutic phenomenology. Questionnaires and interviews were conducted with 9 chronically ill AYAs to elicit in-depth accounts of their lived experiences of using *SGL*. Descriptive statistical analysis was performed on questionnaire data. Phenomenological data analysis, informed by hermeneutic analysis, was used to analyze interviews.

**Results.** AYAs reported positive experiences with *SGL* and valued the ability to engage in various content while having few participation expectations. They also described psychosocial benefits, including reprieve from illness, sense of community, and solidarity through mutual understandings and shared experiences.

**Significance of the results.** Findings highlight the usefulness and acceptability of a virtual palliative psychosocial care program for chronically ill AYAs. Findings also suggest the effectiveness of *SGL* and support using an OHC to meet the psychosocial needs of AYAs. This study can guide future programming and implementation of online palliative psychosocial care programs in other hospital settings, resulting in similar beneficial and meaningful experiences.

**Introduction**

Adolescents and young adults (AYAs) with chronic and life-limiting illnesses are a distinct patient population with complex needs. This population continues to grow as survival rates improve for conditions that were previously fatal, such as cancer, cystic fibrosis, and sickle cell disease (Dunbar et al. 2019; Sawyer et al. 2007). Managing the complexities of living with chronic illnesses in conjunction with the psychosocial dynamics of adolescence and young adulthood presents unique challenges for AYAs (Avutu et al. 2022; Barnett et al. 2016; Sawyer et al. 2007). Lack of adequate psychosocial support can make it difficult for AYAs to adjust to life with chronic illness and puts them at high risk for poor psychosocial functioning (Rosenberg et al. 2018, 2021; Zebrack and Isaacson 2012), highlighting the importance of providing age-appropriate programs and services that are tailored to the needs of this population as a standard of care (Clark and Fasciano 2015; Weaver et al. 2016).

Palliative care programs, which address physical, emotional, psychosocial, and spiritual dimensions of illness and are often introduced early in the disease trajectory (Abdelal et al. 2021; Pritchard et al. 2011; Rosenberg and Wolfe 2013; Wiener et al. 2015), are an important aspect of care for chronically ill AYAs as they provide many benefits to patients' health and well-being (Clark and Fasciano 2015; Rosenberg and Wolfe 2013; Wiener et al. 2015). However, it is common for palliative care to only be designed for pediatric or adult patients, with AYAs then inappropriately lumped into one of these 2 groups. This has created a gap in care as palliative approaches utilized for pediatric or adult populations are not adequate for AYAs (Clarke 2015; Rosenberg and Wolfe 2013). AYA research supports using developmentally appropriate programs to provide palliative care that addresses the multifaceted psychosocial needs of AYAs (Avutu et al. 2022; Barnett et al. 2016; D'Agostino et al. 2011; Holland et al. 2021; Pennant et al. 2020; Pinkerton et al. 2018). Among AYAs, psychosocial palliative care programs integrating aspects of social support, peer relationships, and technology have been recommended (Avutu et al. 2022; Lea et al. 2018; Sawyer et al. 2007; Zebrack and Isaacson 2012) and can therefore serve as central focuses of these programs, such as online health communities (OHCs).

OHCs have been recommended for chronically ill AYAs and are often desirable because they can connect AYAs to same-age peers with similar illnesses, and they foster normalcy, relatability, and support (Kaal et al. 2018; Lea et al. 2018; McCann et al. 2019; Pritchard et al. 2011). Illness-related barriers preventing AYAs from accessing peer relationships and psychosocial support can be overcome by using online platforms, with the potential to develop supportive and meaningful relationships that can improve health outcomes and psychosocial well-being (Helms et al. 2015; Kaal et al. 2018; Poku et al. 2018; Pritchard et al. 2011; Waldron et al. 2017; Zebrack 2011; Zebrack and Isaacson 2012). Further, utilizing OHCs for program delivery can be developmentally appropriate and appealing to AYAs (Ho et al. 2014; Kohut et al. 2018; Solberg 2014; Willis and Roynce 2017; Zebrack 2009). Though the benefits of OHCs have been demonstrated among AYA populations, research on using these programs for delivering AYA psychosocial palliative care remains sparse.

### Streetlight program

*Streetlight*, located at the University of Florida (UF) Health Shands Children's Hospital in Gainesville, Florida, is an innovative psychosocial palliative care peer support program for hospitalized AYAs with chronic and life-limiting illnesses that helps AYAs navigate their course of their illness and is introduced early in their disease trajectory (Streetlight 2021; Walker et al. 2022a, 2022b). *Streetlight* provides inpatient and outpatient volunteer visitation services to AYAs aged 13–25 with cancer, cystic fibrosis, sickle cell disease, patients awaiting organ transplantation, and other rare diseases. Volunteer in-patient visitation is designed to foster long-term meaningful relationships, normalize hospital experiences, and enhance quality of life among an especially vulnerable population (Barakat et al. 2016; Barnett et al. 2016; Clark and Fasciano 2015; Walker et al. 2022b). Unique to *Streetlight*, volunteers dedicate a minimum of 2 years of service and receive 8-to-10 hours of program orientation and 60+ hours of ongoing psychosocial palliative care education. More information on program protocol, services, and procedures and patient volume/reach can be found on *Streetlight's* program website and in previous literature related to the program (Puig et al. 2015; Walker et al. 2022a, 2022b).

**Table 1.** Operationalizations of evaluation aspects assessed in the study

Evaluation aspect	Operational definition
Usefulness	Perception of engagement in SGL to be beneficial or helpful; the value or worth of SGL as a program; how relevant or helpful SGL was to participants; practical worth
Acceptability	General impressions about suitability of SGL, especially for the AYA patient population; degree of willingness to participate in SGL; extent that SGL is appropriate (enjoy using it; likely to use it again; likely to recommend to others)
Effectiveness	SGL was doing what it intended to do, including encouraging authentic relationships, enabling continuity of relationships made during in-patient admissions, and reducing isolation through virtual support

### Streetlight gaming league program

The *Streetlight Gaming League* (SGL) is an OHC established as a complementary component of *Streetlight* that offers a virtual source of peer-based social support, online gaming, and community events for patients in *Streetlight* (Streetlight Gaming League 2021; Walker et al. 2022a). Housed within the *Streetlight* program, SGL focuses on addressing psychosocial aspects of palliative care and aims to encourage authentic relationships, enable continuity of relationships made during in-patient admissions, and reduce isolation through virtual support via a private Discord (Discord n.d.) server when in-person support might not be feasible.

Patients are invited to join SGL during hospital admissions and outpatient appointments. Patients consent or assent (with legal guardian) to a behavioral code of conduct outlining community behavior standards and Discord terms of service. While hospitalized, patients also have access to current-generation gaming consoles, online subscriptions, secure internet access, and a library of downloaded games. In Discord, patients can participate in select events and channels related to topics of interest. During hospitalization and following discharge, patients can stay in Discord and participate, however, desired, ranging from active contribution to passive observation. *Streetlight* staff and volunteers moderate the server and facilitate patient-centered events.

### Objectives

Current understanding of programs targeting AYAs' psychosocial needs through online platforms is underdeveloped, despite AYAs' continued experience of unmet needs (Abdelal et al. 2021; Barakat et al. 2016; Holland et al. 2021; Pennant et al. 2020; Smith et al. 2013). We aimed to evaluate the usefulness, acceptability, and potential effectiveness of SGL (Table 1) through an assessment of chronically ill AYAs' lived experiences participating in the SGL program. A secondary objective was to explore whether participation style influenced participants' experiences. There is value in understanding how AYAs participate in SGL, given research suggesting that how individuals participate with a platform could impact their experiences (Gerson et al. 2017; Li 2016; Malinen 2015; van Mierlo 2014). Exploring participation style could also inform implementation of SGL.

### Methods

The well-being of AYAs was at the forefront of our study, ensuring it was conducted in a manner that emphasized participants' voices

(Kent et al. 2012; Rosenberg and Wolfe 2013). Given our objective of evaluating the usefulness, acceptability, and potential effectiveness of the SGL through the lived experiences of participating AYAs, we utilized a qualitative evaluation approach grounded in hermeneutic phenomenology, an interpretive research paradigm. Hermeneutic phenomenology was selected because it aligned with our inquiry about lived experiences of members of a community interacting with others in a shared online environment, allowing for an in-depth exploration and interpretation of chronically ill AYA patient experiences and how experiences manifest for different individuals using SGL (Bynum and Varpio 2018; Flood 2010; Lopez and Willis 2004; Neubauer et al. 2019). Phenomenological studies have expanded to include individuals using online spaces, providing further support for this approach (Aarts et al. 2015; Bush et al. 2019; Osler 2020). Our study was guided by the consolidated criteria for reporting qualitative research checklist to improve rigor, trustworthiness, and credibility (Tong et al. 2007). Approval was obtained from the UF Institutional Review Board (No. 202000235). This study is part of ongoing research efforts to evaluate and manualize the *Streetlight* program (Walker et al. 2022a).

### Participant recruitment

Based on recommendations for phenomenological studies, we aimed to conduct at least 8 interviews (Mason 2010; Vasileiou et al. 2018). Participants were recruited using purposeful and snowball sampling, ensuring selection of information-rich cases. To be included, participants were current *Streetlight* patients; currently participating or had previously participated in the SGL; between ages 13–25 (the age group served by *Streetlight*); able to speak, read, and write in English; and cognitively able to participate. Inclusion criteria were verified by *Streetlight* staff (Director and Assistant Director). *Streetlight* staff posted a recruitment flyer to the Discord's general chat and directly messaged users reiterating the recruitment post and inviting individuals to participate. Interested participants provided electronic informed consent (adults) or consent with assent (minors) via research electronic data capture (REDCap), a secure, web-based platform designed to support data capture (Harris et al. 2009).

### Data collection

Data collection materials were developed using extensive, iterative vetting procedures with quantitative and qualitative experts and *Streetlight* staff. The questionnaires and interview guide were first shared with experts for feedback and revised. We then sent them back for another round of feedback. This process continued until all materials had been fully discussed, revised, and improved. Later, materials were shared with the *Streetlight* staff to receive their expert opinion as people who work directly with AYA patients and SGL members. Both individuals reviewed materials and provided feedback on their suitability and whether phrasing of content was appropriate. All materials were revised according to the feedback received.

Questions and subscales from psychosocial, palliative care, and online participation style research informed development of our data collection materials (Escobar-Viera et al. 2018; Hanley et al. 2019; Kulandaivelu et al. 2018; Li 2016; Pennant et al. 2020; Walker et al. 2019). The participation style questionnaire was informed by research conducted on active/passive participation among platforms similar to SGL (e.g., social media, online communities,

and social networking sites) and active/passive subscales from research (Escobar-Viera et al. 2018; Gerson et al. 2017; Hanley et al. 2019; Li 2016; Malinen 2015; Verduyn et al. 2017). Elements were adapted to fit the context of this study. Research in the areas of psychosocial and palliative care for chronically ill AYAs guided development of interview questions, including the wording, use of balanced questions, introduction segment, and appropriate number of questions (Kulandaivelu et al. 2018; Pennant et al. 2020; Walker et al. 2019). The evaluative aspects and phenomenological underpinnings of our study were considered when drafting questions to ensure experiences of this unique population were being investigated and evaluation questions were being assessed. Literacy levels were assessed using the WebFX readability test tool (WebFX n.d.) and were considered satisfactory if they were between 6th and 8th grade literacy levels (Clinton-McHarg et al. 2010). Data were collected between September 2020 and January 2021.

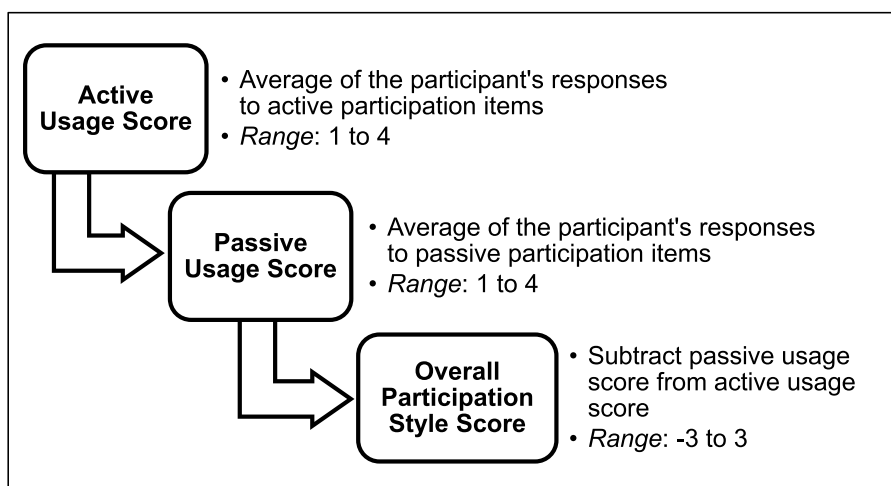
Participants were sent 2 electronic questionnaires via REDCap. The demographic questionnaire asked were about age, gender, length of *Streetlight* and SGL membership, and prior video game experience. The participation style questionnaire collected data to provide descriptors about how participants engaged with SGL (actively or passively). Active participation is when users are more engaged with content and content creation (posting, replying, and facilitating exchanges) (Li 2016). Passive participation is when users are more inclined to content consumption or monitoring content (browsing, viewing, and lurking) (Escobar-Viera et al. 2018; Verduyn et al. 2017). Participation style scoring (Figure 1) was used as a stratification tool to generally explore similarities and differences in how experiences manifest for individuals using SGL. After completing questionnaires, participants completed a 1:1 interview with a trained team member. Interviews were conducted online and recorded using Zoom® technology, lasting between 30 and 60 minutes. Participants were sent a \$25 gift card after interview completion. Sessions were transcribed using Otter.ai® software and reviewed for accuracy.

### Data analysis

Descriptive analyses were performed using SAS Software (version 9.4), which included participation style scoring. Interviews were stratified by participation style scores prior to qualitative analysis to explore whether participation style influenced participant experiences. Qualitative analyses were performed by 3 trained researchers using NVivo 12 software. Data analysis was guided by phenomenological and hermeneutic principles described in the literature (Ajjawi and Higgs 2007; Bynum and Varpio 2018; Crist and Tanner 2003; Flood 2010) and consisted of 4 stages: immersion, identifying meaning units, developing final meaning units, and establishing final themes and subthemes. Data analysis was completed independently for the first 2 stages, including immersion and identification of meaning units and collaboratively via weekly meetings for the final 2 stages of analysis. Researchers engaged with the hermeneutic circle throughout the analysis.

### Results

Table 2 presents participant characteristics. Nine AYAs participated in the study. Explanations for not completing interviews included illness-related and COVID-19-related reasons that impacted the ability to participate. Six AYAs were identified as male and 3 as female. A majority ( $n = 7$ ) of participants were between the ages



**Fig. 1.** Scoring process for active and passive participation styles used to stratify study participants into 2 groups (active or passive) based on their overall participation style score. Participants stratified into the active participation style group had a positive overall participation style score. Participants stratified into the passive participation style group had a negative overall participation style score.

**Table 2.** Demographic characteristics and descriptive statistics of AYA participants (*n* = 9)

Characteristics	Frequency (%)
Gender	
Male	6 (66.7)
Female	3 (33.3)
Age group (years)	
13–17	2 (22.2)
18–25	7 (77.8)
Prior experience playing video games	
Yes	9 (100)
No	0 (0)
Characteristics	Mean (SD)
Age (years)	19.8 (2.5)
Time being <i>Streetlight</i> member (months)	42.2 (28.9)
Time being <i>SGL</i> participant (months)	22.9 (10.2)

of 18 and 25. Of the participants, 5 had active participation styles and 4 had passive participation styles.

### Shared experiences and perceptions

Analysis revealed similarities among AYAs’ experiences and perceptions of *SGL*. Seven themes were shared among active and passive participants: (1) uniqueness of AYA patients, (2) acceptability of *SGL*, (3) user choice in content, (4) freedom from participation expectations, (5) reprieve from illness, (6) solidarity in chronic illness, and (7) sense of community. Themes and subthemes are shown in [Table 3](#). Supporting quotes are provided in [Table 4](#).

#### Uniqueness of AYA patients

Several participants discussed their unique experiences with being chronically ill at a young age. This was described as separate from pediatric or adult patient needs, due to the distinct phenomena associated with experiencing a period of developmental

transitions while simultaneously receiving care. Some participants explained that being an AYA patient was like being in a gray area with a noticeable gap in care (quote 1). Further, participants felt out of place in hospital settings because they lacked designated age-appropriate programs and appropriate bedside manner. Participants further mentioned that *SGL* is one of the first programs in their experience to address the AYA care gap.

#### Acceptability of *SGL*

Participants were overwhelmingly positive when describing *SGL*. Most participants perceived the *SGL* as a beneficial program for those who use it because it provided social interactions, tailored care for AYAs, comfort when hospitalized, and a more normal teen experience, emphasizing its positive impact on chronically ill AYAs (quotes 2–3). When asked to discuss negative aspects of the program, few were identified by participants. However, some limitations of the social groups were noted, including group composition, frequency of engagement, and anxiety upon joining. One participant noted the lack of female participants as a drawback (quote 4). Others expressed they would like more people to actively participate. Passive participant uniquely noted that initial integration into the Discord could be anxiety-provoking, but this was soon overcome with the benefits of both peer and content engagement.

Passive participants provided perceptions about *SGL* delivery, explaining that the online format provided an alternative mechanism for engagement and allowed for increased accessibility, helping to overcome geographic barriers (quotes 5–6). One participant directly explained they could only participate because of the online format. Some also mentioned the online format was helpful during COVID-19 lockdowns when in-person interactions were not available. Additionally, many participants endorsed expanding *Streetlight* and *SGL* to other hospitals, explaining similar AYA-specific programs would be valuable and likely provide other AYAs with similar benefits (quotes 7–8).

#### User choice in content

Participants expressed autonomy over modes of engagement within the *SGL* platform, such as gameplay, chatting via the Discord server, or keeping up with the topic-based Discord channels. Most participants agreed that *SGL* appeals to multiple interests and has become a multifaceted platform with something for everyone, even



**Table 3.** Themes and subthemes among AYA participants with accompanying definitions and subtheme operationalizations

Themes and definitions	Subthemes	Subtheme operationalizations
<i>Uniqueness of AYA Patients:</i> Distinct phenomena of a patient group separate from pediatric or adult patient groups, who are experiencing a period of developmental transitions while simultaneously receiving care	–	Experiences of AYA patients dealing with chronic illness during an already difficult developmental period as AYAs, coupled with a lack of age-appropriate services and designated spaces for care in the hospital setting
<i>Perceptions of the SGL:</i> Participant's insights into aspects of the SGL	Positive experiences	Positive experiences and interactions using the SGL platform that correlate to participants' perceptions that the program is beneficial to those who use it
	Limitations of SGL social groups	Aspects of the SGL that participants believed were lacking or could be improved upon, such as social group composition and frequency of engagement
	Accessibility of online format (P)	Provides a mechanism for engagement due to availability of online format, which helped with barriers to in-person interactions
	Expansion of SGL and <i>Streetlight</i> to other Hospitals (P)	The perception that implementing similar AYA-specific programs in other hospitals would likely provide similar benefits
<i>Relieve from Illness:</i> Expressed relief from the negative effects associated with living with chronic illnesses	Distraction from illness	Outlet for AYA patients to take their minds off their illnesses, treatments, or other illness-related issues
	Something positive to look forward to	AYAs eagerly anticipated engaging with the SGL when readmitted to the hospital because the SGL helps make tough days better and improves the mood of users
	Enhanced in-hospital experiences	SGL improves hospital visits by providing an escape from the rough parts of being in the hospital (i.e., boredom, isolation, and loneliness) through entertainment and social interactions
<i>Solidarity in Chronic Illness:</i> Having the common experience of being sick at a young age, allowing SGL users to relate and support one another as they collectively navigate living with a chronic illness	Mutual understandings through shared experiences	Being able to comprehend and empathize with what other SGL users are going through because they have been through it too; comfort knowing you do not have to explain everything you are experiencing because people in the SGL already understand
	Sense of normalcy (P)	Helps participants feel like a typical AYA who is not sick or who never had an illness; helps them gain a bit of normal back into their everyday lives; reduces feelings of loneliness and isolation relevant to chronic illness diagnosis
<i>User Choice in Content:</i> Participant autonomy to choose from a variety of media options for engagement within the SGL platform	Appeals to multiple interests	SGL is not exclusively for gaming; it has evolved into something much bigger that encompasses other interests in addition to gaming
	Exposure to new things	Trying different activities outside of normal engagement based on the desire for expansion of interests or recommendations from others
<i>Freedom from Participation Expectations:</i> Participant-cultivated low-pressure environment, coupled with no program requirements for involvement, allows users to engage as desired	Flexibility of participation	Can be social on your own terms without requirement to participate in a certain way; SGL fosters a low-pressure environment allowing for AYAs to elicit what works best for their individual needs
	There for you, if needed (P)	A comfort knowing the SGL is available to AYA patients if they need a place to go, regardless of how often you participate
<i>Sense of Community:</i> Feeling of belongingness and genuine camaraderie among a group of similar individuals	Facilitates connection and communication	Provides opportunities for positive social engagement among same-age peers and continuity of relationships within and beyond hospitalizations
	Offers social support	Acknowledgment of feeling generally supported by other AYA patients, similar to that of a support group
	Friendships and relationships (A)	Expression of a mutual, close-knit bond between participants in the SGL
<i>Mental Health Benefits (A):</i> Cognitive and emotional advantages experienced by SGL users who actively participate	Mechanism for healing process (A)	Participation in the SGL promotes therapeutic benefits to the mental and emotional challenges that come from living with a chronic illness
	Impact demeanor and/or mood (A)	SGL interactions/connections help make tough days better, improve the mood of users, and helps with their mental health

(A) indicates active participant theme/subtheme; (P) indicates passive participant theme/subtheme.

if gaming is not a top interest (quotes 9–10). Although SGL was intended to bring AYAs together through gaming, participants felt it had evolved into something more “involved” and “inclusive,”

bringing people together with a variety of interests. SGL also exposed patients to new things, allowing them to try activities outside of normal engagement (quote 11).

**Table 4.** Themes, quote numbers, and exemplary quotes

<b>Shared AYA Experiences and Perceptions</b>	
<i>Uniqueness of AYA patients</i>	
1	So, having something like <i>Streetlight</i> is cool because it is that sort of in between and they do sort of approach you like more of an adult but not so much a child. It's kind of hard to explain; it is a weird like area to be in. Because then like on the pediatric floors, I'm treated like a child. Like people will lie to me about like weird things with my meds or like just not take me seriously and things like that. And that does get annoying. But yeah, I'd say that <i>Streetlight</i> is very good about treating you like an adult and, you know, taking you seriously but also recognizing that like you're still pretty fragile and pretty like I don't know, new to life. Like you're new to dealing with all of this, if that makes sense. Like it's just a weird place to be in ... Like they at least make an effort, I guess is the thing, because a lot of other areas of treatment don't recognize you as like this weird in between age. So, it's nice that there's even something there for us ....[3P]
<i>Perceptions of the SGL</i>	
Positive experiences	
2	I've had so many chronic illnesses for so long ... I've been in a lot of groups, and <i>Streetlight's</i> Gaming League has been one of the best groups I'm in ... I mean, the <i>Streetlight</i> Gaming League is great. [15P]
3	Other than that, to have fun and just make it a welcoming space for everybody where you can learn and have fun and not have to worry about all the negative effects that are going on with your life. [6A]
Limitations of SGL social groups	
4	I'm pretty sure most of the group is male, which kind of sucks sometimes. Because I already don't have a lot of female friends in real life. So, it would be nice to be able to make some in that group. [3P]
Accessibility of online format (P)	
5	Yeah, well, also, this, this is something I can do online. Like, I don't have to ... I don't have to go anywhere. And I like if it was a group that you meet with I like in real life, I would not be able to do it. I just couldn't because I live 6 hours away. [1P]
6	I can like ... if I'm not feeling well or I need to go home ... I can just say "hey, I'll talk later" and go take a nap because it's online so I don't have to go out and meet people. And texting and kind of doing the chat – it's a lot easier than ... talking face-to-face or even on a voice call. [15P]
Expansion of SGL and <i>Streetlight</i> to other hospitals (P)	
7	Yeah, I definitely think that at least something like this would be so valuable to so many hospitals. Because right now it is like only little, little kids get like the "Make A Wish you want to go to Disney sort of package" where like people our ages, we're kind of just boxed up with adults. And it's treated like that's how it is. You know what I mean? So yeah, I definitely think in some form something like this would be beneficial to a lot of people. [3P]
8	I think having a program like the <i>SGL</i> , for other teens would be great. Because I mean, I love it ... The <i>Streetlight Gaming League</i> would be really cool to have for others so that, you know, they can get that sense of community and a sense of solidarity together. I've always said that <i>Streetlight</i> should be in every other hospital or a program like <i>Streetlight</i> ... But no, I think definitely just – if there was a way to get <i>Streetlight</i> into other hospitals, it would be really, really nice. [15P]
<i>User choice in content</i>	
Appeals to multiple interests	
9	But then you have all the different subcategories. So, like I said earlier ... it's not just gaming. I can go on there and I can talk about books that I've read, I can talk about movies I've watched, music I've listened to, umm, there's a cooking subgroup which I try to post on when I make all my new dishes because I love to cook. [15P]
10	[...] with the Discord server, it's more like interacting with people in like the group chats. And so, it's either talking about pictures that they posted, like of their cats or dogs, or like, some of them even do really, really good art. Like I know [username]'s roommate is like really, really good at art. And they'll show that to us. It's actually great because it's like things that we never knew before. [7A]
Exposure to new things	
11	[...] I've tried to get into some of the other channels just to kind of expand my interests and friend group and it's worked. [15P]
<i>Freedom from participation expectations</i>	
Flexibility of participation	
12	[...] you don't have to talk about everything, you don't have to say how it made you feel, or how you are currently feeling. You just kind of come there, you do things, you can find things that you like, you can post your art, you can do whatever you want, really. And it can be nice to do that. [1P]
13	Talking about only lung transplant, and hearing about coordinators or things that's going on, is – it tends to get tiring after a while. Whereas like, with the Discord server, it's just we talk about, we can talk about what's happening with us. Or we can talk about other things if you just don't want to talk about what's happening with us at that moment. [7A]
There for you, if needed (P)	
14	I mean ... it's very much up to your discretion when and how you want to participate. Like, you can sign up for these activities that we do, but you don't have to do all of them, you can just do a few of them. You can tune in when and how you want to. You can always silent the chats like, it's, no one's pressuring you to do anything. It's all just whatever you want to do when you want to do it. And that's nice. Like I can message the chat at like 3 in the morning if I want to ... It's just there for you when you need it. [3P]

(Continued)

Table 4. (Continued.)

15	And so, I think that it is mainly for that feeling of just being able to do what you want to do. And be kind of just there. [1P]
	<i>Relieve from illness</i>
	Distraction from illness
16	I like it because it allows me to talk to the ones inside the hospital and give them some time to not think about what they're doing and just focus on actually acting like their age and having fun. And just ... playing video games instead of worrying about the life situation that they're going through. [6A]
17	I guess um, I just want to say it's very, it's very helpful, you know, when we have a bunch of people together, having fun, playing together, you know. So, you don't have to think about other things that are very concerning like an illness. [9P]
18	It's a great distraction, it's great to feel like you kind of belong somewhere and have somewhere where the focus isn't your ailment, whatever it may be. [3P]
	Something positive to look forward to
19	Now, from time to time, like it has made bad days seem a little less bad because I, you know, I just go and do something I enjoy ... And so, it was kind of just, I don't know, I like gaming, and I figured that it might be something that would lighten up my day. Because at the time, my days weren't very good ... So, it kind of gives us a little bit of reassurance if I ever go back into the hospital. I know I can, you know, I have something that I will be able to do. And at least it won't all be like the whole hospital duties type stuff where you get woken up at 4am and all sorts of stuff. And it won't all be that rough. [1P]
20	The most positive part was that I had something to fill my day with, you know, people to meet, people to talk to. It wasn't just me being by myself the whole time. [2A]
21	I'd say that, um, like, at least I'm kind of a little bit more like, it's not so like doom and gloom when I have to go to Shands. Because I'm like, "Oh, at least I'm gonna see [person's name], or I'm gonna see [volunteer name]" ... So that's nice. It's kind of a little bit of a positive spin I get to put on things whenever I go down there. [3P]
	Enhanced in-hospital experiences
22	It really does make a difference when you're in the hospital for weeks at a time and, you know, your friends can't see you because you're a couple hours away from home or whatnot. So, it's really nice to have them there. And have the Gaming League there to interact with. [15P]
23	Um, whenever I would be admitted into the hospital, I remember at least someone would come to my room to visit me. And I remember I could be like, feeling the most down. Or maybe just not feeling great either with maybe pain that I'm having, or just being disappointed from being admitted into the hospital, and one of the <i>Streetlight</i> members would come into my room. And I remember just my whole demeanor, and my, my mood would just change. And I would, I would just be so much happier. And I would get sad when they'd have to go. But it was okay because they would always come back to visit me. [4A]
	<i>Solidarity in chronic illness</i>
	Mutual understandings through shared experiences
24	When I talk to the person with the illness I can kind of understand them, kind of better, because like I'm going through that too. [9P]
25	There's definitely a few transplant patients in the SGL, so, like sharing our experiences, or even just like, talking about the doctors or nurses that we liked. It like, makes us feel less alone in what's happening. [7A]
	Sense of normalcy (P)
26	Because it can be really like lonely and kind of [pause] kind of put you in a position of like you feel like an outcast kind of. So, yeah, I really like that during this timing of going through this especially that I do have those people and even outside of in-person relations, there's the Discord and all of that. So yeah, that's really nice. [3P]
27	I guess, good as in normal. I think that's what I want to say ... Makes me feel like I never had an illness. Like I did a while ago. [9P]
28	So, having the <i>Streetlight</i> Gaming League, where it's just, you know, we all, we all have health issues, that's okay. Let's just move on. It's nice, because it, it really adds a sense of normalcy, that you don't get a lot when you're chronically ill. [15P]
	<i>Sense of community</i>
	Facilitates social connection and communication
29	I can talk to people with similar interests, just kind of get some community since you know, times of COVID, can't leave the house. So, it's nice to feel like I can at least go there and go in a room with other people and just have conversation. [15P]
30	It's definitely, I'd say kept most of us sane, like talking to people. Because quarantine gets really, really annoying and lonely, and just isolating. So, like, being able to talk to at least like 2 or 3 people while we're here or while we're in our houses has definitely been pretty great. [7A]
31	I know that I'm actually this Halloween um I'm planning to visit [username], her name is [participant name], um, this coming up, and I'm like, really praying because I'm going on my, my second internship for my program, so I really hope I don't have to work that weekend. And it's gonna be so fun. We're gonna play games watch movies. [4A]
	Offers social support
32	And knowing like, the few conversations I have had with people or seen with people, like everyone is so, so nice. And if you do go in chat saying "hey, I like this is getting to me, I need to talk about it," like somebody will respond and be so, so sweet and so understanding, no matter who it is. [3P]

(Continued)

Table 4. (Continued.)

33	If I was like, feeling down maybe one day or like, maybe I wasn't feeling good one day, maybe extra tired. Or maybe if I was having like, joint pain or something like that, I'd be like, "Hey, guys, um sorry I haven't really been talking much today. You know, I've been really tired today." And then, you know, I would just get a whole bunch of support from different people is like, "Oh, it's okay. I hope you feel better soon." And it's, it's provided like, amazing support group for me ... we just support each other. And then like, the Streetlight mantra says, like, "we get to carry each other." [4A]
34	It's actually been pretty great. It's like a huge family. So, you can go there for any kind of support that you need. Or, like, anything that you think, like, you've accomplished, and you just want to like, show it to somebody. [7A]
	Friendships and relationships (A)
35	Um, because everyone that I've met in Gaming League, they're just all really good friends of mine. And they're really like the only true friends that I really have. And like, I wouldn't trade that for anything in the world. [4A]
	<b>Differing AYA experiences and perceptions</b>
	<i>Mental health benefits (A)</i>
	Mechanism for the healing process (A)
36	The sense of community actually, like helps with the healing process. Like not physically, but like mentally 'cause being in the hospital takes a huge emotional toll ... It's just - it's another way to, like, relieve some of the like, stress and mental things going on with being or having a chronic illness. [7A]
37	Like I said it was, it was definitely a rough ride as I was going through that stuff, but like they helped me out a lot. And they like took me in, too, like, 'cause I didn't have anybody besides like my mom taking care of me at that point. [8A]
38	I thought my depression was going to take back over. And then <i>Streetlight</i> started offering D&D and movies ... And people are like, you could play Among Us on the phone. You could start like actually doing multiplayer games with people, that's a game people actually like. And it's like, I am not so depressed now. [6A]
	Impact demeanor and/or mood (A)
39	My roommate notices if I ever just have one down day. And I see like conversations go on ... And I'm just laughing to myself ... I'll be like, a little bit happier than I was previously. [6A]
40	Um, <i>Streetlight Gaming League</i> has definitely helped me a lot. Especially with, like, my mental health, as well as physical health ... I'm definitely much happier. [4A]

(A) indicates active participant theme/subtheme; (P) indicates passive participant theme/subtheme.

### Freedom from participation expectations

The SGL environment was described as low pressure with few participation expectations or requirements, allowing participants to decide how to engage with the platform and its users. Many participants mentioned flexibility of participation as a programmatic strength. Participants appreciated the ability to engage as much or as little as they wanted and to be social on their own terms (quote 12). Some also appreciated the freedom to discuss topics or disclose information only if desired, especially topics related to being sick or personal illness experiences (quote 13). Moreover, several passive participants mentioned that regardless of participation frequency, the platform is always "there for you when you need it," explaining SGL holds space for all types of participants and is always available, without expectations (quotes 14–15).

### Relieve from illness

All participants expressed that SGL provided much-needed relief from the negative effects associated with living with chronic illnesses, offering a source of distraction and acting as an outlet for AYAs to take their minds off their illnesses, treatments, and illness-related issues (quotes 16–18). Participants also mentioned SGL gave them something positive to look forward to when readmitted to the hospital. Being rehospitalized can be difficult, but the guarantee of SGL access helped make tough days better and improved the mood of users (quotes 19–21), providing participants with a positive outlook on at least one aspect of their hospital visit. Additionally, several mentioned the SGL enhanced their in-hospital experiences, providing an escape from the rough parts

of being in the hospital (i.e., boredom, isolation, and loneliness) through entertainment and social interactions (quotes 22–23).

### Solidarity in chronic illness

Participants found comfort in knowing that SGL users had the common experience of being sick at a young age, allowing users to relate to and support one another as they collectively navigated living with chronic illness. This feeling of solidarity was attributed to participants' mutual understandings that came from their shared experiences. These similar experiences allowed participants to comprehend and empathize with what other users were going through (quotes 24–25). Moreover, some participants felt relieved that they did not have to explain their experiences of being sick; rather, there was an unspoken understanding about what it was like to be an AYA patient. Having mutual understandings provided a common ground to build relationships, connect, and interact with each other like typical people their age, allowing the focal point of social interactions to center around traditional AYA interests.

One benefit mentioned by passive participants was regaining a sense of normalcy into their everyday lives. Participants explained how SGL helped them feel normal by reducing feelings of isolation and loneliness (quotes 26–28). Rather than feeling like a patient with a chronic illness, SGL helped them feel like typical AYAs who get to hang out, play games, and act their age, adding to their experience of solidarity.

### Sense of community

Many participants expressed a feeling of belongingness and genuine camaraderie, resulting in a sense of community. SGL



facilitated social connection and communication by providing opportunities for positive social engagement among same-age peers, including during the COVID-19 strict lockdown protocols (quote 29–30). Social connection and communication also allowed for continuity of relationships beyond hospitalizations. One participant excitedly mentioned their upcoming trip to meet a fellow user in person (quote 31). Participants also mentioned that the *SGL* offered social support, adding to an overall sense of community. They described feeling generally supported by others, similar to being in a support group (quotes 32–34).

Specifically, among active participants, the mention of close friendships was common. They explained that the friendships were one of the best aspects of *SGL* and expressed feeling a mutual, close-knit bond between participants. Active participants also talked about how they use the platform to hang out with and share things with friends they made through *SGL*. It seemed many of them experienced a strong bond and strong appreciation for these friendships (quote 35).

### Differing experiences and perceptions

There was one differing theme specific to active participants' experiences: mental health benefits (Table 3). Active participants described experiencing cognitive and emotional advantages from *SGL* participation. Several explained the *SGL* was a mechanism for their healing process, wherein participation promoted therapeutic benefits to mental and emotional challenges associated with chronic illness. One participant explained how *SGL* engagement helped with their depression and anxiety (quotes 36–38). Active participants also mentioned interactions and connections impacted their demeanor and improved their overall mood, helping with their mental health. This included feeling happier and making day-to-day life better, especially days when they were not feeling well (quotes 39–40).

### Discussion

This study evaluated the usefulness, acceptability, and potential effectiveness of a psychosocial palliative care online support program for chronically ill AYAs by assessing patients' lived experiences with the *SGL*. *SGL* is a novel and innovative program aimed at addressing an existing care gap by incorporating AYAs' preferences for online interventions into its delivery.

Overwhelmingly, AYAs had positive experiences, viewing *SGL* as a beneficial program, including during COVID-19. One salient aspect was the freedom to engage as desired without participation requirements and flexibility to elicit what worked best for their needs. When compared to more formal support groups involving stricter participation requirements, AYAs enjoyed the absence of interaction obligations. The ability to engage on their own terms allowed for a low-pressure environment and an AYA-centric space in which users continued to engage. This suggests that providing more choice in how AYAs utilize psychosocial support programs might be beneficial, potentially leading to increased engagement (Wiener et al. 2015).

Additionally, though advertised as a "gaming" league, a key aspect contributing to positive experiences was AYAs' autonomy to choose how they engaged, including but not limited to gaming. *SGL* appeals to multiple interests and allows users to try new activities and experience new content. As such, the *SGL* has evolved to continually meet patients' psychosocial needs. Real-time patient feedback encouraged *Streetlight* to change the program name from

*Streetlight Gaming League* to *Streetlight Gaming and Online Team (Streetlight GO)* as a programmatic adjustment to better reach patients who may benefit from Discord communication but are less interested in gaming.

This program also provided participants a reprieve from illness. Notably, *SGL* served as a distraction from everyday complexities of being sick by providing an outlet to temporarily focus on something other than their illnesses. This aligns with AYA research, suggesting the importance of online platforms as a distraction from illness-related issues and boredom while hospitalized (Kohut et al. 2018; Lea et al. 2018). AYAs were relieved to have a space to escape while spending virtual time with people their own age. AYAs eagerly anticipated engaging with *SGL* when they were readmitted, knowing it would provide social interactions and an escape from the difficult parts of hospitalization. Moreover, *SGL* provided online interactions during COVID-19 when in-person visitors were not permitted, which may demonstrate an opportunity to engage AYAs with illnesses that require isolation or limited in-person exposure (Cheung and Zebrack 2017; Helms et al. 2015; Lea et al. 2018; Pritchard et al. 2011; Zebrack and Isaacson 2012).

Another salient aspect of *SGL* was the solidarity that emerged from the shared experience of being sick at a young age. AYAs' shared experiences allowed for mutual understanding between users, fostered participants' ability to empathize, and validated patients' experiences. Because of patients' mutual understanding, no one felt their chronic illnesses needed to dominate every conversation or be the only way they could relate. Rather, this solace allowed AYAs to transcend their patient status and become a group of AYAs who feel normal and get to forget their illnesses for a while. These findings align with a study that found having shared experiences led to reduced isolation and feeling more deeply understood (Waite-Jones and Swallow 2018). Participants' expressions of solidarity also contributed to a sense of community wherein connecting with AYAs through shared experiences and mutual understandings resulted in an online community where people were supportive and helped improve their lived experiences. This study also provides further evidence that solidarity developed from understanding through shared experiences can serve as a mechanism of support for AYA peers (Breuer et al. 2017; Pennant et al. 2020).

While experiences mostly overlapped across participation styles, there were some differences. Active participants discussed mental health benefits and emphasized close friendships made through *SGL*. In contrast, passive participants noted the sense of normalcy experienced in *SGL* and were less likely to describe their relationships as friendships. Still, passive participants appreciated *SGL*'s online delivery because it made engagement more accessible, providing unlimited access to same-age peers and support. These differences indicate that participation style may influence an AYA's experience and, therefore, diverse needs and preferences should be considered when developing palliative care programs. Efforts should be made to present a holistic program that engages all participation styles to equitably serve each patient and provide a wide breadth of opportunities for engagement (Devine et al. 2018; Hanley et al. 2019; Treadgold and Kuperberg 2010).

Our study demonstrates that having access to and connecting with same-aged AYA peers can result in a sense of community and psychosocial benefits, aligning with existing literature (Breuer et al. 2017; Cheung and Zebrack 2017; Pennant et al. 2020; Treadgold and Kuperberg 2010; Zebrack et al. 2006). Our findings parallel research by Cheung and Zebrack (2017) that found facilitating peer interactions among AYAs help address psychosocial needs

and is a critical component of AYA care. Results from the current study further support the importance of peer interactions for AYAs, how these interactions can be facilitated online, and the accompanying benefits of such interactions. AYAs need opportunities to engage in age-appropriate activities with same-age peers to aid healthy development and shift the focus away from illness-related factors (Pennant et al. 2020; Waite-Jones and Swallow 2018; Zebrack et al. 2016). Lastly, this study highlights the importance of further investigating the role OHCs and online platforms play in promoting social support within palliative and chronic care models.

Programs addressing the multifaceted nature of AYA illnesses are crucial and should be complemented with programs that provide a reprieve from illness, sense of community, participation autonomy, and meaningfulness. SGL is a good example of this as it is housed within the larger *Streetlight* program. *Streetlight* offers in-person palliative care and psychosocial services to patients through its in-hospital volunteer program and other in-hospital services (Walker et al. 2022a, 2022b). To complement the volunteer-based focus of *Streetlight*, SGL provides a platform that facilitates relationships between AYA peers with similar illnesses. While these programs may not be directly applicable to all settings, the platform (mode of delivery) could be implemented by hospitals serving AYAs, resulting in similar beneficial and meaningful experiences. Future research could undertake larger studies to determine the potential of such a program for wider dissemination across hospital settings.

### Limitations

Our study describes a specific sample of AYA patients, so findings cannot be generalized to all AYA populations. Selection bias may have occurred as AYAs were a self-selecting group who chose to participate. Findings mostly highlighted perspectives of older AYAs, with the youngest being 17 years old. Perspectives of younger AYAs may differ from our findings. All participants reported having prior video game experience before SGL participation. While this aligns with reports that young people play video games at high rates (Perrin 2018), it could have biased findings. Lastly, historical context must be considered as this study occurred during COVID-19, which likely impacted data collected from participants.

### Conclusion

This study expands the body of knowledge surrounding online palliative psychosocial care programs for chronically ill AYAs, bringing us closer to filling the AYA care gap. Utilizing a staff-moderated Discord server can be effective, developmentally appropriate, and appealing to AYAs. Findings can guide future programming and implementation of similar programs. Though program context might differ, we provide insight into a technological tool that could be used in other settings and adapted to fit the needs of different AYA patient populations.

**Conflicts of interest.** The authors declare no conflicts of interest.

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