

Original Article

Cite this article: LeBeau K, Raponi JM, Walker D, Swygert A, Marchi E (2024) Social support among chronically ill adolescent and young adult patients using a hospital-based online health community as part of a palliative care program: A qualitative study. *Palliative and Supportive Care*, 1–10. <https://doi.org/10.1017/S1478951524000208>

Received: 15 August 2023

Revised: 13 December 2023

Accepted: 18 January 2024


Keywords:

palliative care; adolescents and young adults; psychosocial support; online health community; peer support

Corresponding author: Kelsea LeBeau;

Email: kelsea.lebeau@va.gov

Social support among chronically ill adolescent and young adult patients using a hospital-based online health community as part of a palliative care program: A qualitative study

Kelsea LeBeau, PH.D., M.P.H.^{1,2} , Jayne-Marie Raponi, PH.D., M.P.H.¹, Drew Walker, M.S.³, Anna Swygert, M.DIV.⁴ and Emily Marchi, M.S.⁴

¹College of Public Health and Health Professions, University of Florida, Gainesville, FL, USA; ²U.S. Department of Veterans Affairs, VA North Florida/South Georgia Veterans Health System, Gainesville, FL, USA; ³Department of Behavioral, Social and Health Education Sciences, Rollins School of Public Health, Emory University, Atlanta, GA, USA and ⁴Department of Pediatrics, University of Florida Health, Gainesville, FL, USA

Abstract

Objectives. Chronically ill adolescent and young adult (AYA) patients experience barriers to accessing psychosocial support/palliative care, increasing their risk for negative psychosocial outcomes. Online health communities (OHCs) have been recommended for AYAs as part of palliative care support programs; however, we lack research investigating palliative care programs targeting AYAs' psychosocial support needs that are delivered virtually and able to engage with patients both during and beyond inpatient admissions. *Streetlight* is a palliative care program designed for chronically ill AYAs. Developed as a complementary component that extends beyond the hospital setting, *Streetlight Gaming and Online Team (SGOT)* is an OHC aimed at facilitating social support to influence psychosocial outcomes. We investigated the existence and enactment of social support among chronically ill AYAs using *SGOT* and compared this to existing online social support categories to determine which support types are present within *SGOT*.

Methods. This was a qualitative phenomenological study. We performed deductive thematic analysis based on existing online social support categories. Nine semi-structured interviews were conducted with *SGOT* participants.

Results. Social companionship/belonging, esteem/emotional, and informational support were most prevalent within *SGOT*. Thirteen subthemes emerged representing how social support impacted AYAs' psychosocial wellbeing. Notably, coping with/managing illness, sense of community and normalcy, recommendations and advice, and shared interests unrelated to illnesses were subthemes that resonated with AYAs and added value to their experiences.

Significance of results. *SGOT* is an impactful OHC used to meet AYAs' social support needs. What makes *SGOT* especially unique is its virtual delivery, wherein AYAs can conveniently maintain beneficial relationships with other chronically ill same-aged peers. AYAs need spaces where they can feel normal and access continuous support, both within and beyond inpatient admissions. This study enhances our understanding of online AYA psychosocial support programs. Findings can be used by healthcare professionals to implement similar palliative care and psychosocial support programs.

Introduction

Adolescent and young adult (AYA) patients with chronic and life-limiting illnesses are a unique population that continues to report unmet support needs (D'Agostino et al. 2011; Holland et al. 2021; Kent et al. 2013; Tsangaris et al. 2014), which are associated with lower health-related quality of life, worse mental health, and decreased psychosocial functioning (Abdelaal et al. 2022; Sawyer et al. 2017; Smith et al. 2013; Zebrack and Isaacson 2012). Research suggests AYAs' unmet support needs are attributed to the lack of age-specific healthcare programs and services that focus on psychosocial aspects of care (D'Agostino et al. 2011; Holland et al. 2021; Richter et al. 2015). Age-appropriate social support programs are necessary to fully address the needs of this vulnerable group and mitigate adverse effects of the AYA patient experience (LeBeau et al. 2023; Pennant et al. 2020; Richter et al. 2015).

Social support is crucial for AYAs, influencing autonomy, identity formation, and overall wellbeing (Allen et al. 2022; Linebarger et al. 2014). Frequent hospitalizations, alienation from

healthy peers, and exclusion from normative socio-developmental experiences make maintenance of supportive relationships challenging and increases risks for negative outcomes (Allen et al. 2022; Cheung and Zebrack 2017; Kent et al. 2013; Zebrack and Isaacson 2012). Research demonstrates that chronically ill AYAs who develop supportive relationships and social connectedness report improved self-efficacy, psychological wellbeing, disease/illness coping, and quality of life (Abdelaal et al. 2022; Breuer et al. 2017; Kaal et al. 2018; Poku et al. 2018; Tsangaris et al. 2014; Zebrack and Isaacson 2012). Support from same-age peers with similar diagnoses is especially valuable as it alleviates feeling abnormal; provides comfort knowing others can relate to experiences; and assists with processing illness experiences (Breuer et al. 2017; Kent et al. 2013; Lea et al. 2018; LeBeau et al. 2023; Mobley et al. 2018; Pennant et al. 2020; Rujimora et al. 2023; Tsangaris et al. 2014).

Facilitating opportunities for support can impact AYA care (Breuer et al. 2017; Cheung and Zebrack 2017; Kent et al. 2013; Mobley et al. 2018; Rujimora et al. 2023), especially opportunities that minimize infection risks while maximizing peer relationships and support (Kohut et al. 2018; Lazard et al. 2021; Lea et al. 2018; Rabin et al. 2013). Online health communities (OHCs) are virtual spaces that can be significant sources of support and empowerment for chronically ill AYAs. Support facilitated through OHCs can provide similar benefits to those of in-person relationships (Cheung and Zebrack 2017; Kohut et al. 2018; Lea et al. 2018). Furthermore, social support found in offline settings also exists in online contexts (Kaal et al. 2018; Kohut et al. 2018; Lea et al. 2018; Nick et al. 2018). Researchers recommend OHCs for chronically ill AYAs as an alternative to traditional modalities to facilitate support and promote positive health outcomes (Devine et al. 2017; Kaal et al. 2018; Kirk and Milnes 2016; Kohut et al. 2018; Rabin et al. 2013; Solberg 2014).

Clinical palliative care program

Streetlight at UF Health is a palliative care program helping chronically or terminally ill AYAs navigate the course of their illness and is often introduced early in their disease trajectory. *Streetlight* focuses on Designated Palliative AYA patients ages 13–30 living with cancer, cystic fibrosis, sickle cell disease, diseases requiring organ transplants, and other rare diseases, or who have been admitted at least 3 times in recent years. The *Streetlight Gaming and Online Team (SGOT)*; at time of data collection, named the *Streetlight Gaming League* is an OHC established as a complementary component of the larger *Streetlight* program (LeBeau et al. 2023), in which AYAs are invited to join during hospital admissions and outpatient appointments. *SGOT* addresses psychosocial aspects of palliative care and enables continuity of relationships by extending beyond the inpatient setting.

SGOT involves inpatient gaming and virtual community. While hospitalized, patients have access to current generation gaming consoles equipped with online subscriptions, secure internet access, and a library of downloaded games. Additionally, patients can participate in virtual community through a private Discord (n.d.) server moderated by *Streetlight* staff and volunteers, featuring 36 interest-specific text channels and 6 voice channels. Patients can continue to access Discord following discharge and participate as desired. To maintain a safe environment for patients, *Streetlight* has several structures and safeguards in place for *SGOT*, including a behavioral code, Discord moderation, and crisis resources and emergency services (see Appendix 1 for more detail). Additional information about *Streetlight* and *SGOT* can be

found on their website and in related publications (LeBeau et al. 2023; Rujimora et al. 2023; Walker et al. 2022a, 2022b).

Objective

Despite knowledge regarding the delivery of programs for chronically ill AYAs and needs expressed by this population, we lack research on age-appropriate programs targeting AYAs' psychosocial support needs that are delivered virtually and extend beyond the hospital setting. As part of a larger project and ongoing research efforts to manualize the *Streetlight* program (LeBeau et al. 2023; Rujimora et al. 2023; Walker et al. 2022a, 2022b), we aimed to address the research gap of AYAs' unmet support needs by investigating the existence and enactment of social support among chronically ill AYAs using an OHC. We also compared this with existing online social support categories to understand which support types are present in this online space.

Methods

A description of this study's phenomenological qualitative research design has previously been described (LeBeau et al. 2023). Briefly, we used a constructivist research paradigm and a hermeneutic phenomenological approach to investigate the lived experiences of *SGOT* participants, considering points of view from different patients and using all perspectives to represent the phenomenon (Neubauer et al. 2019). We selected hermeneutic phenomenology because it facilitates in-depth exploration and interpretation of AYA patients' lived experiences of social support and emphasizes meaning and meaningfulness as ascribed by participants (Bynum and Varpio 2018; Neubauer et al. 2019). Our study was guided by the COREQ checklist to ensure rigor, credibility, and trustworthiness (Tong et al. 2007). We obtained approval from the University of Florida Institutional Review Board (#202000235).

Data collection

Based on recommendations for phenomenological studies, we aimed to conduct at least 8 interviews (Vasileiou et al. 2018). Recruitment for this study mirrored recruitment for *Streetlight* itself. As such, this study was not focused on a specific diagnosis; rather, the goal was to reach a sampling of various patients participating in the *SGOT* as there is value in investigating a variety of conditions and illnesses (McNeil et al., 2019). To understand the breadth of experiences, we recruited AYAs with various illnesses, such as cancer, cystic fibrosis, sickle cell disease, diseases requiring organ transplant, and other rare diseases. Eligible participants were *Streetlight* members; currently participating or had previously participated in *SGOT*; between the ages of 13 and 30 years; able to speak, read, and write in English; and cognitively able to participate. We recruited AYAs using purposeful and snowball sampling to ensure selection of information-rich cases and allow for any members to participate, regardless of disease trajectory and psychosocial history. *Streetlight* staff assisted with recruitment by posting the recruitment flyer to the Discord general chat and directly messaged AYAs inviting them to participate. Participants provided electronic informed consent (adults) or consent with assent (minors) via REDCap (Harris et al. 2009). Data collection materials underwent an extensive vetting process, described previously (LeBeau et al. 2023). We collected data between September 2020 and January 2021.

Table 1. Initial online social support coding scheme used for deductive approach to reflexive thematic analysis

Type of social support	Operationalization	Examples
Esteem and emotional	Information that a person is esteemed, cared for, and accepted	Being held in high esteem, offer help with one's emotional state, or express acceptance, caring, liking, loving, respect, concern, empathy, or sympathy
Social companionship and belonging	Sense of social belonging and having others to engage with in shared social activities	Expressions of inclusivity or spending time together; sharing leisure time
Informational	Advice, feedback, suggestions, information, guidance, references	Offering help in the form of advice, constructive feedback or affirmation, new information or perspectives, or references to new resources
Instrumental	Tangible aid and services	Offering financial aid, providing material resources, or taking on a responsibility

Participants completed a researcher-created questionnaire via REDCap (Harris et al. 2009) capturing self-reported demographic characteristics. For accuracy, *Streetlight* staff provided data on length of *Streetlight* and *SGOT* membership for participants. Participants also completed a 30–60 minute one-on-one semi-structured interview with a female researcher (KL) trained in qualitative methodology. The interview guide consisted of 12 open-ended questions informed by online social support and AYA literature (Breuer et al. 2017; Nick et al. 2018), divided into 4 sections according to online social support types: esteem/emotional, social companionship/belonging, informational, and instrumental (Nick et al. 2018) (Supplemental file 1). As interviews progressed, questions were added to address emerging references to experiences, and confirm or clarify themes described by participants (e.g., member-checking) (Pennant et al. 2020). We conducted and recorded interviews using Zoom®. We transcribed interviews via transcription software and reviewed for accuracy. No repeat interviews were conducted, and transcripts were not returned to participants for comment or correction. AYAs received a \$25 electronic gift card for participating.

Data analysis

We analyzed demographic data using SAS Software (version 9.4) to describe sample makeup. We used a predominantly deductive approach to reflexive thematic analysis to analyze interview data, where existing research/theory provide the lens through which data are coded and interpreted (Braun and Clarke 2021, 2023). We referenced existing online social support categories to develop the initial coding scheme for analysis (Table 1) (Braun and Clarke 2021; Nick et al. 2018).

Two researchers (KL, JMR) conducted analysis via Word and Excel using the 6-phase process, moving between

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>SGOT</i> participant (months)	22.9 (10.2)

phases as necessary: data familiarization; systematic data coding; generating initial themes; developing and reviewing themes; refining, defining, and naming themes; and writing the report (Braun and Clarke 2021, 2023). The researchers independently analyzed data during phases 1–3 using the coding scheme, wherein initial codes and themes were informed by existing online social support categories. After completing separate analyses, themes/subthemes were collaboratively compared and finalized during phases 4 and 5. We employed a more inductive approach for subtheme development, which comprised descriptive and interpretive elements, and involved querying our assumptions to produce a richer understanding (Braun and Clarke 2021). Data saturation was discussed during collaborative meetings about the analysis process. Themes do not represent distinct entities but rather are interrelated constructs that together capture the experiences of AYA participants.

Results

Nine AYAs participated in the study, with 6 identifying as male and 3 identifying as female. Mean age was 19.8 years ($SD = 2.5$), and 7 participants (78%) were between the ages of 18 and 25 years. On average, participants had been members of *Streetlight* and *SGOT* for 3.5 and 1.9 years, respectively (Table 2). AYAs consistently highlighted the existence and enactment of social support within *SGOT*. Participants perceived the 4 online social support categories, with all participants agreeing if they needed a certain type of support, they felt confident they could seek it out from other AYAs. Social companionship/belonging was the most prevalent support type experienced, followed by esteem/emotional and informational support. Instrumental support was the least prevalent (Table 3). Themes and subthemes are in Table 4. Supporting quotes are provided in Table 5.

Social companionship and belonging

Experiences of social companionship/belonging support were captured into 4 subthemes: embeddedness, inclusivity and common interests, sense of community, and sense of normalcy.

Table 3. Coding frequencies and percentages for the 4 types of online social support

Type of online social support	Frequency count	Percentage
Social companionship and belonging	64	41.3%
Esteem and emotional	43	27.7%
Informational	37	23.9%
Instrumental	11	7.1%
Total	155	100%

AYAs described being attached to others and deeply ingrained in the *SGOT* group, much of which was attributed to their connections and interactions with others, and a sense of closeness from these relationships (quote #1). Some mentioned others' actions made them feel socially integrated and like they were a prominent part of each other's lives, creating a sense of unity (#2).

Participants also discussed feelings of inclusivity, explaining others' actions made them feel like there was a place for them (#3). Several AYAs mentioned *SGOT*'s welcoming nature added to its inclusivity and their sense of belonging (#4). Ensuring a welcoming environment was important to *SGOT*'s culture. AYAs were appreciative of being welcomed with no judgment and desired to do the same for others who join. Additionally, participants described support through shared interests (i.e., gaming, cooking, art, music, memes, anime, pets), and the time spent together engaging in leisure/recreational activities within *SGOT* (i.e., online gameplay). Participants mentioned sharing and enjoying many interests with others made them feel like they belong. More importantly, these

commonalities provided pathways to build deeper relationships, encouraging mutual disclosure (#5).

Most participants expressed a sense of community, feeling fortunate to be part of a supportive group. The support and community from AYAs with shared experiences also alleviated feelings of isolation and loneliness (#6 and 7). Additionally, participants expressed that their sense of community often stemmed from being part of a group where people are going through the same thing. Shared experiences were related to their experiences as chronically ill AYAs, providing participants with a special bond, or form of kinship, which contributed to their feeling of community (#8).

Lastly, participants expressed a sense of normalcy that emerged from exposure to AYAs with similar health issues, explaining that it was comforting to see others talk about their illnesses because it made them feel more normal in their own illness experience (#9). Moreover, the commonality from which *SGOT* is based – living with chronic or life-limiting illness – provided the same “normal” baseline where AYAs could act like regular teens. Participants appreciated how normal it felt to talk about illness, making these conversations as normal as talking about the weather (#10). They also appreciated that *SGOT* participation alleviated the pressures of being defined by their illnesses, making the focus less about being sick and more about their own teenage-related interests and who they are as a person (#11).

Esteem and emotional

Esteem/emotional support fell into 3 subthemes: feeling cared for and listened to, acceptance and validation, and coping with and managing illness. Connections between AYAs were perceived as supportive, making AYAs feel cared for and listened to by others. Participants mentioned other AYAs improved their mood on days

Table 4. Online social support themes and subthemes with accompanying definitions

Theme	Subthemes	Definitions
Social companionship and belonging support	Embeddedness	Sense of being embedded in a network or being attached to other AYA patients in <i>SGOT</i>
	Inclusivity and common interests	Expressions of inclusivity or spending time together with other AYA patients through leisure/recreational activities; having shared interests made AYAs feel like they belong to <i>SGOT</i> and helped them build relationships with other AYA patients
	Sense of community	Feeling like you belong to a group of people who understand each other's experiences, are supportive of one another, and provide friendship; comfort in knowing others have felt the same way because they have similar experiences as AYA patients
	Sense of normalcy	Sense of commonness that emerges from being around a group of patients with similar health issues; providing AYA patients with the same normal baseline where they can act like normal teens; alleviating the pressure of being defined by illness or feeling like an outlier
Esteem and emotional support	Feeling cared for and listened to	Feeling like AYA patients have someone they can talk to who will listen and care for them just the way they are; being willing to help other AYA patients and care for them; providing hope and a listening ear
	Acceptance and validation	Feeling accepted, validated, and that other AYA patients are genuinely interested in them as a person; feeling like they matter or are held in high esteem
	Coping with and managing illness	Offering help in managing other AYA patients' emotional states; helping AYA patients assess their situations or self-evaluate; providing AYA patients with relief or distraction from illness

(Continued)

Table 4. (Continued.)

Theme	Subthemes	Definitions
Informational support	General information	Provision of general knowledge, information, and perspectives from what AYA patients perceive as reliable sources
	Recommendations and advice	Providing advice, feedback, guidance, or suggestions, which centered around general interests and more specific interests within designated Discord channels
Instrumental support	Tangible aid or assistance	Practical help provided by another AYA patient; somebody actually doing something for someone else in <i>SGOT</i>
	Perceived availability of instrumental support	Belief that help would be available if needed and would be received if a patient asked for it

where they would otherwise feel stuck and alone (#12). Participants enjoyed developing friendships within *SGOT* where they could talk for hours with AYAs who understood the challenges associated with illness (#13 and 14).

Additionally, participants overwhelmingly described feeling accepted and validated through their *SGOT* interactions. Participants felt their contributions mattered and members responded with genuine care and interest (#15). Participants felt like they were part of a pseudo family where they could be themselves without worry (#16).

SGOT offered a space where AYAs could receive help in managing their emotional state and cope with and/or manage their illness, which helped with stress relief, mental health, isolation, and loneliness. Participants valued that they could speak about their illness as much or as little as they wanted, and when they wanted to talk, participants appreciated *SGOT* as an alternative to speaking with family members (#17). Moreover, *SGOT* provided relief from various aspects of illness. For many, knowing they shared experiences with AYAs contributed to feeling less alone in their illnesses and the accompanying uncomfortable experiences (#18). Not all participants were initially engaged to the full potential of *SGOT*, but through continued exploration they found their place and were grateful for *SGOT* participants keeping them sane on hard days (#19).

Informational

Most participants did not typically use *SGOT* for seeking information; however, they agreed that if they needed informational support, it would be available. Informational support had 2 subthemes: general information and recommendations and advice. Participants felt confident other AYAs could provide valuable knowledge and perspectives. They felt comfortable asking questions and trusted the responses of *SGOT* participants (#20 and 21).

Many participants also valued that they were receiving recommendations and advice from people they could trust and who had relevant life experiences, as opposed to Googling answers on the internet (#22). Recommendations and advice varied, and often centered around AYAs' general interests or interests specific to the designated *SGOT* Discord channels (#23). Additionally, participants described being exposed to new topics they might otherwise have not come across (#24).

Instrumental

Instrumental support was comprised of 2 subthemes: tangible aid or assistance and perceived availability of instrumental support.

Some participants mentioned the receipt of help from another participant in which that person directly assisted them with something, such as troubleshooting Discord issues or beating video game levels (#25 and 26). Most participants perceived the availability of instrumental support and if needed felt that *SGOT* members would be willing to help. Some also stated they would be willing to offer instrumental support if someone asked (#27 and 28).

Discussion

Our study demonstrates the existence and enactment of social support within *SGOT*, highlighting support type prevalence and demonstrating the relevance and meaningfulness to chronically ill AYAs. AYAs mostly used *SGOT* for social companionship/belonging, esteem/emotional, and informational support. Findings are consistent with research indicating AYAs desire opportunities for emotional, informational, and social companionship/belonging support (Breuer et al. 2017; Cheung and Zebrack 2017; Lea et al. 2018; LeBeau et al. 2023; Pennant et al. 2020; Rujimora et al. 2023). Our study adds to existing research by demonstrating that *SGOT* is an impactful OHC which can be used to meet AYAs' psychosocial support needs.

AYAs experienced social companionship/belonging support through a strong sense of community wherein they felt like they belonged to a group who understood each other and provided authentic friendships. This sense of community reduced feelings of isolation and improved AYAs' ability to cope with difficult events. The ability for *SGOT* to provide this type of support is especially valuable considering the isolation and loneliness resulting from living with chronic and life-limiting illnesses (Kent et al. 2013). This aligns with research demonstrating the importance of supportive relationships for AYA patients (D'Agostino et al. 2011; Kent et al. 2013; Lazard et al. 2021; LeBeau et al. 2023; Rabin et al. 2013; Rujimora et al. 2023; Zebrack and Isaacson 2012).

Facilitating a sense of normalcy was another way social companionship/belonging support was meaningfully experienced, which aligns with studies suggesting AYAs provide support through a sense of normalcy (Lazard et al. 2021; LeBeau et al. 2023; Pennant et al. 2020). *SGOT* created an environment where everyone has an illness history, resulting in a new normal baseline where participants can be regular people instead of chronically ill patients, which alleviated feelings of abnormality and insecurity that often arise from being around non-sick peers (Pennant et al. 2020). AYAs appreciated *SGOT* was not strictly focused on having an illness but instead allowed participants to act like normal teenagers or young adults (LeBeau et al. 2023; Pennant et al. 2020). Findings are consistent with research documenting the positive impact of

Table 5. Quote numbers³ and exemplary quotes for themes and subthemes

Theme	Subtheme	Exemplar quotes	
Social companionship and belonging support	Embeddedness	#1. I mean, feels like friends, or at least as close as I can get to friends.... We're just a big group of...acquaintances that are stuck together and happily stuck together.... A sense of family that's not focused on illnesses. (Participant 15)	
		#2. It's definitely just like all the positivity and the in-depth conversations that happen ... they make you feel like they want to hear what you're saying, or they want to see what you're doing, and actually be a part of your lives without actually being there in person ... it's not even just gaming. It's more just like a regular ... Discord server where we all talk about different things ... we all do different things. And it's just all of us coming together to be part of that. (Participant 7)	
	Inclusivity and common interests	#3. I never feel stupid or too young or too old, or I never feel out of place. Just because everyone's always so encouraging and so inclusive. (Participant 15) #4. I feel definitely like I was welcomed [with] open arms. And that goes for everybody else that joins [SGOT]. Whenever you join in the little chat space, there's like a little welcome message. And right off the bat, as soon as you join, there'll be a few other people like, "Hello ... Welcome to the [SGOT] family." ... as soon as you join, you know, it's just a hoard of love and friendship together. It's just really amazing that I get to be a part of this community. And I love seeing new people join every day. I love seeing that welcome message pop up in the general chat. And I type in their name, I say, "Hey, welcome," you know, just to make sure that everyone has the same experience that I've had. (Participant 4) #5. We just get like the camaraderie built up by playing the game [Dungeons & Dragons] together...I had a conversation with people on there that I met playing the [Dungeons & Dragons] campaign. And we became friends over a couple of weeks. And then after a while, we just started talking about, like, how we were in [SGOT] and what happened to us and things like that. (Participant 8)	
Sense of community	Sense of community	#6. Everyone in [SGOT], [they're] really amazing people. It's like words ... can't even explain how good this community has been to me. It's just really amazing that I get to be a part of this community. (Participant 4) #7. They make me feel supported and give me a sense of community that, again, I'm not alone. I mean, they're always so supportive. (Participant 15) #8. I definitely feel some sort of kinship with them just because I know what we're all going through is very hard, regardless of each individual person's diagnoses or whatever treatment they're going through. I know it's just hard being sick at this age. So yeah, there's definitely some sort of kinship there. And I definitely feel kind of almost protective over them.... I guess I would say that I feel like a part of a community there. (Participant 3)	
		Sense of normalcy	#9. Seeing others that have mentioned having G tubes or stuff. It's cool, because not a lot of ... I mean, you think of feeding tubes, and you think of either babies or really old people. So, to see that I'm not the only teen around that has a feeding tube or has a port or a PICC line or something, it's really nice to see that I'm not alone ... (Participant 15) #10. It's nice [because] people aren't so like, "Oh, my God, that's terrible". It's kind of just like talking about the weather. Like, it's just a thing ... just makes me feel more normal ... like I kind of have a friend group or a group of people that I can talk to these things about and not have it be such a big deal. (Participant 3) #11. ... it takes away from some of the reminders that, "oh, yeah, this is a medical group". And for lack of better terms, we're all screwed up.... So having the [SGOT], where it's just, you know, we all have health issues, that's okay. Let's just move on. It's nice because it really adds a sense of normalcy that you don't get a lot when you're chronically ill. (Participant 15)
			Esteem and emotional support

(Continued)

Table 5. (Continued.)

Theme	Subtheme	Exemplar quotes
	Acceptance and validation	<p>#15. When I'm having an active conversation, I always feel like they're actually interested in what I'm saying ... I mean, they express genuine interest...it feels like what I'm saying matters and that it's not just "Oh, another person commenting in a group chat with a bunch of people." (Participant 15)</p> <p>#16. Yeah, it really does make you feel like a whole second pseudo family, where you can just come in and be accepted and not have to worry about having any person really down you ... (Participant 6)</p>
	Coping with and managing illness	<p>#17. It definitely helps because...on top of them being around my age and ... being like my general demographic, but also having those things in common. And knowing what's going on with each other ... you can talk with [them] about things like that, rather than having your parents or your family, like if you don't yet want to talk to them about that, or if you don't feel comfortable talking with them about that. It's just ... it's another way to relieve some of the stress and mental things going on with being or having a chronic illness. (Participant 7)</p> <p>#18. Relieving ... I know that sounds bad, that sounds really, really bad. But it's relieving because you're actually talking to people who went through the same thing as you... Like I had cancer. And some people have the immunity thing where they have to take pills to get better. Or they have to be in the hospital and have a bag go through them, or they have to constantly have nurses come in and all that. It's just nice knowing that I'm not the only one that had to deal with all this hospital "funness" where I had to actually get a port inside and have [inaudible] go through my heart and have ALL my hair fall out. And essentially feel like I might be dying at one point of this. It's nice feeling that there are other people that went through it, and you can actually talk to each other and make each other feel better and not have to focus on that negative thing that's going on. (Participant 6)</p> <p>#19. And it's really funny because I was there for about a month and, like I said, I don't like meeting new people. So, every time they came in, I would tell them ... "I'm not interested [in] anything". And that happened for about a month until I got really bored. And [then I was like] "alright, I'll come down [to] join you guys [in] whatever you do". And after that ... I want to say they kept me sane throughout a lot of it. And I thank them for that a lot. (Participant 8)</p>
Informational support	General information	<p>#20. I feel like people who have knowledge would respond to me. Because, like I said, even if they're [not on Discord at the time], I feel like they'd probably get to it when they could ... and if they have [the] information. (Participant 8)</p> <p>#21. [People post information] about ... housing in general because there's a bunch of new students who are either starting to move out on their own or people who are coming to Gainesville ... and just like different things that helps with what you should look for, what you need, things like that with moving into a new place. (Participant 7)</p>
	Recommendations and advice	<p>#22. Oh, yeah, definitely. There's enough of us to have the life experience to get pretty good advice, honestly. Because there's also the varying age ranges of everybody in the group. But everybody's extremely helpful and would actually give good advice, from my opinion ... [because] personal life experiences tend to be better than Googling things. (Participant 7)</p> <p>#23. There's a channel in the [SGOT] Discord.... It's the cooking channel. And ever since that was put in, I remember a lot of people who are into cooking or, like, want to learn and try out different recipes. Like, we'll give our little tips or tricks that we can do during cooking. Like, I remember in the creativity challenge that we did a few months ago, cooking was like a big thing during creativity challenge, like everybody was sharing their creations. And I remember that being super fun ... there's a few people [in SGOT] where they'll give like recommendations on maybe like a game that they played, or a show that they've watched. Um, I remember talking to [participant name] a lot ... And he's recommended a lot of shows to me that I've watched and they're really good shows... And I think pretty much anyone, like, depending on the situation or conversation that's going on, um, there'll be at least somebody that might recommend something. (Participant 4)</p> <p>#24. I look at the anime channel to find out things that I think might be something good to watch. Or, you know, I just kind of look around. And there have been times where I've [seen] something that's for somebody else. And I've been like, well, that kind of applies to me too. (Participant 1)</p>
Instrumental support	Tangible aid or assistance	<p>#25. Yeah, we have [username] who knows a bit more about the Discord if you don't really know how to do it, he will literally call you and be like, "Okay, this is how you do it." And he talks you through it and helps you out how to do all this. (Participant 6)</p> <p>#26. I was playing Zelda. And I was like, "I don't know how to get through this shrine, what is going on?" And we kind of talked through it a little bit. So, like, I know, if I went on there, especially with video games, if I was like, "how do I do this?" I could get help. (Participant 3)</p>

(Continued)

Table 5. (Continued.)

Theme	Subtheme	Exemplar quotes
	Perceived availability of instrumental support	#27. I've never personally asked for help. So, maybe, but I'm pretty sure if I did someone would probably help me. (Participant 8) #28. Oh, yeah, definitely. Yeah, everyone's extremely helpful. And I would do the same for them. (Participant 7)

^aQuote numbers are formatted with a # and the number of the quote. This is how quote numbers are referenced in the article, as well.

same-aged peers (Cheung and Zebrack 2017; Mobley et al. 2018). When developing psychosocial programs for AYAs, the desire to feel normal and have access to programs that do not focus solely on illness-related factors should be considered to help facilitate healthy development and a sense of normalcy (Pennant et al. 2020).

AYAs perceived unique value in esteem/emotional support offered within *SGOT* because other AYAs can relate and provide perspective on illness and treatment in ways people without illness cannot, including managing illnesses and appraising situations as less threatening (D'Agostino et al. 2011). Having similar illness experiences contributed to ease in talking to others and feeling understood. These shared experiences also helped AYAs feel less intimidated by their illnesses, encouraging proactive coping (D'Agostino et al. 2011; Rujimora et al. 2023). Experiences of esteem/emotional support were not solely defined by illness. Participants expressed interest in what other AYAs had to say and what was going on in their lives and provided comfort for non-illness-related life events. Furthermore, *SGOT* acted as a judgment-free zone where AYAs did not have to worry about being anyone but themselves – illness and all. For some, this was one of the first times in their lives where they felt accepted and validated for who they were as a person, adding to the importance of esteem/emotional support in this OHC.

SGOT also provided a supportive space where AYAs could find relief from illness. Relief was generally discussed in 2 ways. First, *SGOT* participation provided relief in knowing other people understood what living with chronic illness encompasses without needing to explain, including the day-to-day difficulties and undesirable parts of treatments. AYAs appreciated being part of a group with such a deep level of understanding that did not require talking about their illness or feeling pitied. This aligns with research highlighting the value of AYA peers (Pennant et al. 2020) and a meta-analysis that found evidence supporting technology-assisted interventions that provide relief from treatments (Zhang et al. 2022). Second, there was relief in knowing illness was not the focal point of their interactions. Access to *SGOT* was a much-needed relief from everything else going on in life and a supportive place where AYAs could dialogue about non-illness topics. Connecting to same-age peers with similar illness experiences has been shown to be a crucial type of support, sometimes more beneficial than support received from family and friends (Breuer et al. 2017; D'Agostino et al. 2011; Kent et al. 2013; Mobley et al. 2018; Pennant et al. 2020; Rabin et al. 2013). As AYA research continues to develop, understanding the impact of a program like *SGOT* on caregiver/family burden for certain types of support is important, especially given their role in an AYA patient's continuum of care and increased dependence on caregivers for support needs that chronically ill AYAs experience (Devine et al. 2017; Pennant et al. 2020).

Many responses indicated social companionship/belonging and esteem/emotional support were interconnected. Some participants

described being more emotionally engaged and vulnerable because they had developed close relationships and felt embedded in the *SGOT* community. Conversely, others explained the receipt of esteem/emotional support facilitated the development of deeper connections and relationships. Both support types seemed to influence each other in a cyclical way and provided opportunities for the other to exist. These support types may provide AYAs with necessary psychosocial resources to mitigate the adverse effects of illness and make life feel more meaningful and manageable.

We found *SGOT* was not primarily used to seek disease-related information. Most informational support was in relation to recommendations and advice outside of their needs as chronically ill AYAs. However, participants were confident that if they had disease-related questions, they would receive a trustworthy answer, which aligns with research suggesting chronically ill AYAs can be an important source of informational support (Lazard et al. 2021; Pennant et al. 2020). While platforms designed for meeting AYAs' health information needs are important (Allen et al. 2022; Lea et al. 2018; Rabin et al. 2013), our study suggests it is also important for AYAs to have space where they can be "normal" teens and young adults and access information related to those needs.

SGOT innovatively uses a Discord server as the main online platform. Discord is cost-effective (free) and available to anyone with internet and a computer/smartphone. Utilizing more popular online platforms can ensure access to programs that are relevant, meaningful, and age-appropriate in their delivery (Abdelaal et al. 2022; Cheung and Zebrack 2017). Our study provides evidence for Discord as a technological tool that can be utilized for AYAs in other hospital settings to facilitate psychosocial support through the development of similar online programming.

What makes *SGOT* unique and meaningful is its virtual delivery and extension beyond the hospital setting, wherein AYAs can conveniently maintain relationships. Treatments and numerous hospital admissions impact the ability to sustain relationships (Cheung and Zebrack 2017; Kent et al. 2013; Zebrack and Isaacson 2012). Recognizing that AYAs require their own specialized supportive care services, many hospitals develop programs for patients while they are admitted, but these programs often do not continue after discharge. Because of its online delivery, AYAs can access *SGOT* anywhere and continue cultivating relationships. This is a novel way to continuously provide supportive/palliative care services after AYAs are discharged, finish treatment, or transition to older adult care settings. Online social support programs addressing AYAs' psychosocial needs could lead to improved patient experiences and positive long-term outcomes. However, additional research is needed to evaluate the effects of such programs, and relevant mediators, on various outcomes of interest (i.e., quality of life differences between participants; differences in age of onset and prognosis of disease; effectiveness of social support by disease outcome; etc.). Understanding these relationships, as well as the

mechanisms driving them, is an important next step for this field of research.

Limitations

Findings should be interpreted in the context of several limitations. First, this study describes a unique sample of AYA patients and findings cannot be generalized to all AYA populations. The small sample size also potentially limits generalizability of our qualitative findings. However, this initial single site study provides a pathway for larger studies to be performed that determine the applicability of such a program for wider dissemination across AYA hospital settings. Second, sampling methods could have resulted in selection bias which could further limit generalizability. Patient participants could be ones most in need of support, omitting other valid perspectives and experiences due to sample composition (Breuer et al. 2017). Third, this study did not include a process for participants if a formal mental health evaluation was determined to be needed. Given the medical and psychosocial challenges experienced by AYAs, future studies involving AYAs should consider including mental health safeguards in their study processes. Fourth, participants largely represented older AYA patients; the experiences and needs of younger AYAs may differ from our findings. Other demographic variables might also be of interest for future research that were not collected for this study and currently are not regularly collected by *Streetlight*, including race, ethnicity, socioeconomic status, employment, and education. Additionally, there remains a need to expand diversity in AYA research to include AYA minorities and more types of chronic and life-limiting illnesses that impact this population and are underrepresented in existing research (Devine et al. 2017). Fifth, it is possible that some AYAs may not have the means to continue SGOT engagement outside of their admission (e.g., lack of access to a smartphone, computer, or internet). *Streetlight* recently benefitted from a Federal Communications Commission grant where they received access to hotspots with unlimited data that could be issued to support SGOT involvement for patients who would not have access to internet otherwise. Similar initiatives could be helpful in reducing some access barriers. Lastly, this study was conducted during the COVID-19 pandemic, which impacted the lives of all participants in the study and likely impacted data collected from them.

Conclusions

SGOT is an impactful OHC dedicated to meeting AYAs' social support needs. Care for AYA patients is inherently multifaceted. AYAs need spaces where they can access continuous support and feel normal, both inside and beyond the hospital. OHCs such as SGOT can be used to meet the unmet support needs of chronically ill AYAs by facilitating social support, providing access to same-aged AYAs with similar experiences, allowing space to experience relief from illness, and promoting normal life activities. This study enhances the current framework of understanding for AYA psychosocial support programs. Findings can be used by healthcare professionals to provide AYAs with the most relevant and meaningful social support programs and may be beneficial for pediatric and AYA hospital units across the country to implement similar programs.

Supplementary material. The supplementary material for this article can be found at <https://doi.org/10.1017/S1478951524000208>.

Acknowledgments. We would like to acknowledge *Streetlight* for making this study possible and thank them for their dedication and support. Thank you to all the *Streetlight* members for welcoming us into this space, sharing your stories, and embodying “we get to carry each other.” Thank you to Dr. Mark Hart, Dr. Jamie Pomeranz, Dr. Erik W. Black, and Dr. George Hack for all your guidance on this dissertation research.

Author contributions. **Kelsea LeBeau:** Conceptualization (lead); methodology (lead); verification (equal); formal analysis (equal); investigation (lead); resources (equal); data curation (lead); writing – original draft (lead); writing – review and editing (equal); visualization (lead); supervision (lead); project administration (lead). **Jayne-Marie Raponi:** Verification (equal); formal analysis (equal); writing – original draft (supporting); writing – review and editing (equal); visualization (supporting). **Drew Walker:** Conceptualization (supporting); software (lead); verification (equal); investigation (supporting); resources (equal); writing – review and editing (equal); visualization (supporting). **Anna Swygert:** Verification (equal); resources (equal); writing – review and editing (equal). **Emily Marchi:** Conceptualization (supporting); verification (equal); investigation (supporting); resources (equal); writing – review and editing (equal).

Funding. This research received no specific grant from any funding agency, commercial or not-for-profit sectors.

Competing interests. None.

Ethical approval. This study was reviewed and approved by the University of Florida Institutional Review Board (#202000235).

References

- Abdelaal M, Avery J, Chow R, et al. (2022) Palliative care for adolescents and young adults with advanced illness: A scoping review. *Palliative Medicine* 37(1), 88–107. doi:10.1177/02692163221136160
- Allen T, Reda S, Martin S, et al. (2022) The needs of adolescents and young adults with chronic illness: Results of a quality improvement survey. *Children* 9(4), 500. doi:10.3390/children9040500
- Braun V and Clarke V (2021) One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology* 18(3), 328–352. doi:10.1080/14780887.2020.1769238
- Braun V and Clarke V (2023) Toward good practice in thematic analysis: Avoiding common problems and becoming a knowing researcher. *International Journal of Transgender Health* 24(1), 1–6. doi:10.1080/26895269.2022.2129597
- Breuer N, Sender A, Daneck L, et al. (2017) How do young adults with cancer perceive social support? A qualitative study. *Journal of Psychosocial Oncology* 35(3), 292–308. doi:10.1080/07347332.2017.1289290
- Bynum W and Varpio L (2018) When I say ... hermeneutic phenomenology. *Medical Education* 52(3), 252–253. doi:10.1111/medu.13414
- Cheung CK and Zebrack B (2017) What do adolescents and young adults want from cancer resources? Insights from a Delphi panel of AYA patients. *Supportive Care in Cancer* 25(1), 119–126. doi:10.1007/s00520-016-3396-7
- D'Agostino NM, Penney A and Zebrack B (2011) Providing developmentally appropriate psychosocial care to adolescent and young adult cancer survivors. *Cancer* 117(S10), 2329–2334. doi:10.1002/cncr.26043
- Devine KA, Monaghan M and Schwartz LA (2017) Introduction to the special issue on adolescent and young adult health: Why we care, how far we have come, and where we are going. *Journal of Pediatric Psychology* 42(9), 903–909. doi:10.1093/jpepsy/jsx101
- Discord (n.d.) <https://discord.com/> (accessed 21 February 2024).
- Harris PA, Taylor R, Thielke R, et al. (2009) Research electronic data capture (REDCap)—A metadata-driven methodology and workflow process for providing translational research informatics support. *Journal of Biomedical Informatics* 42(2), 377–381. doi:10.1016/j.jbi.2008.08.010
- Holland LR, Walker R, Henney R, et al. (2021) Adolescents and young adults with cancer: Barriers in access to psychosocial support. *Journal of Adolescent and Young Adult Oncology* 10(1), 46–55. doi:10.1089/jayao.2020.0027

- Kaal SEJ, Husson O, Van Dartel F, *et al.* (2018) Online support community for adolescents and young adults (AYAs) with cancer: User statistics, evaluation, and content analysis. *Patient Preference and Adherence* **12**, 2615–2622. doi:10.2147/PPA.S171892
- Kent EE, Smith AW, Keegan THM, *et al.* (2013) Talking about cancer and meeting peer survivors: Social information needs of adolescents and young adults diagnosed with cancer. *Journal of Adolescent and Young Adult Oncology* **2**(2), 44–52. doi:10.1089/jayao.2012.0029
- Kirk S and Milnes L (2016) An exploration of how young people and parents use online support in the context of living with cystic fibrosis. *Health Expectations* **19**(2), 309–321. doi:10.1111/hex.12352
- Kohut SA, LeBlanc C, O’Leary K, *et al.* (2018) The internet as a source of support for youth with chronic conditions: A qualitative study. *Child: Care, Health and Development* **44**, 212–220. doi:10.1111/cch.12535
- Lazard AJ, Collins MKR, Hedrick A, *et al.* (2021) Using social media for peer-to-peer cancer support: Interviews with young adults with cancer. *JMIR Cancer* **7**(3), e28234. doi:10.2196/28234
- Lea S, Martins A, Morgan S, *et al.* (2018) Online information and support needs of young people with cancer: A participatory action research study. *Adolescent Health, Medicine, and Therapeutics* **9**, 121–135. doi:10.2147/AHMT.S173115
- LeBeau K, Collins S, Zori G, *et al.* (2023) Evaluating a novel hospital-based online health community to address palliative and psychosocial care factors for chronically ill adolescent and young adult patients. *Palliative and Supportive Care*, 1–12. doi:10.1017/S1478951523000147
- Linebarger JS, Ajayi TA and Jones BL (2014) Adolescents and young adults with life-threatening illness. *Pediatric Clinics of North America* **61**(4), 785–796. doi:10.1016/j.pcl.2014.05.001
- McNeil R, Egsdal M, Drew S, *et al.* (2019). The changing nature of social support for adolescents and young adults with cancer. *European Journal of Oncology Nursing* **43**, 101667. doi:10.1016/j.ejon.2019.09.008
- Mobley EM, Foster KJ and Terry WW (2018) Identifying and understanding the gaps in care experienced by adolescent and young adult cancer patients at the University of Iowa Hospitals and Clinics. *Journal of Adolescent and Young Adult Oncology* **7**(5), 592–603. doi:10.1089/jayao.2018.0023
- Neubauer BE, Witkop CT and Varpio L (2019) How phenomenology can help us learn from the experiences of others. *Perspectives on Medical Education* **8**(2), 90–97. doi:10.1007/s40037-019-0509-2
- Nick EA, Cole DA, Cho S-J, *et al.* (2018) The Online Social Support Scale: Measure development and validation. *Psychological Assessment* **30**(9), 1127–1143. doi:10.1037/pas0000558
- Pennant S, Lee SC, Holm S, *et al.* (2020) The role of social support in adolescent/young adults coping with cancer treatment. *Children* **7**(1) 1–25. doi:10.3390/CHILDREN7010002
- Poku BA, Caress A-L and Kirk S (2018) Adolescents’ experiences of living with sickle cell disease: An integrative narrative review of the literature. *International Journal of Nursing Studies* **80**, 20–28. doi:10.1016/J.IJNURSTU.2017.12.008
- Rabin C, Simpson N, Morrow K, *et al.* (2013) Intervention format and delivery preferences among young adult cancer survivors. *International Journal of Behavioral Medicine* **20**(2), 304–310. doi:10.1007/s12529-012-9227-4
- Richter D, Koehler M, Friedrich M, *et al.* (2015) Psychosocial interventions for adolescents and young adult cancer patients: A systematic review and meta-analysis. *Critical Reviews in Oncology/Hematology* **95**(3), 370–386. doi:10.1016/j.critrevonc.2015.04.003
- Rujimora J, Swygert A, Walker A, *et al.* (2023) “It Becomes a Family I’m a Part of...We Get to Carry Each Other”: Themes from qualitative interview of patients enrolled in an inpatient palliative care support program for adolescents and young adults. *Journal of Palliative Medicine* **26**(9), 1207–1216. doi:10.1089/jpm.2022.0482
- Sawyer SM, McNeil R, McCarthy M, *et al.* (2017) Unmet need for healthcare services in adolescents and young adults with cancer and their parent carers. *Supportive Care in Cancer* **25**(7), 2229–2239. doi:10.1007/s00520-017-3630-y
- Smith A, Parsons HM, Kent EE, *et al.* (2013) Unmet support service needs and health-related quality of life among adolescents and young adults with cancer: The AYA HOPE study. *Frontiers in Oncology* **3**, 75–75. doi:10.3389/fonc.2013.00075
- Solberg LB (2014) The benefits of online health communities. *The Virtual Mentor: VM* **16**(4), 270–274. doi:10.1001/virtualmentor.2014.16.04.stas1-1404
- Tong A, Sainsbury P and Craig J (2007) Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care* **19**(6), 349–357. doi:10.1093/intqhc/mzm042
- Tsangaris E, Johnson J, Taylor R, *et al.* (2014) Identifying the supportive care needs of adolescent and young adult survivors of cancer: A qualitative analysis and systematic literature review. *Supportive Care in Cancer* **22**(4), 947–959. doi:10.1007/s00520-013-2053-7
- Vasileiou K, Barnett J, Thorpe S, *et al.* (2018) Characterising and justifying sample size sufficiency in interview-based studies: Systematic analysis of qualitative health research over a 15-year period. *BMC Medical Research Methodology* **18**(1), 148–148. doi:10.1186/s12874-018-0594-7
- Walker AL, Marchi E, Puig A, *et al.* (2022a) Volunteer-based social support structures and program exposure outcomes in an adolescent young adult palliative care peer support program. *Journal of Palliative Medicine* **25**(8), 1186–1196. doi:10.1089/jpm.2021.0426
- Walker AL, Rujimora J, Swygert A, *et al.* (2022b) A novel palliative care peer support program for adolescents and young adults: Survey and factor analytic study. *Journal of Palliative Medicine* **26**(5), 627–636. doi:10.1089/jpm.2022.0299
- Zebrack B and Isaacson S (2012) Psychosocial care of adolescent and young adult patients with cancer and survivors. *Journal of Clinical Oncology* **30**(11), 1221–1226. doi:10.1200/JCO.2011.39.5467
- Zhang A, Zebrack B, Acquati C, *et al.* (2022) Technology-assisted psychosocial interventions for childhood, adolescent, and young adult cancer survivors: A systematic review and meta-analysis. *Journal of Adolescent and Young Adult Oncology* **11**(1), 6–16. doi:10.1089/jayao.2021.0012