



# Psychiatry and interdisciplinary pediatric palliative care: a scoping review

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**Background:** Current literature highlights the need for psychological support of adolescents and young adults (AYAs) with serious illness, for which pediatric palliative care (PPC) teams are often responsible. This scoping review aims to inventory the most current literature based on discipline, geography, population, methodology, and themes among interdisciplinary PPC teams and the management of psychological distress in AYAs.

**Methods:** Using a scoping review design, a protocol was registered in Open Science Framework (<https://osf.io/fb48n/>). Sources for evidence included online databases (Scopus, PubMed, Embase, PsycInfo, CINAHL), Google Scholar, clinical manuals, texts, national organization webpages, and reference lists, all searched June, 2023. Interviews with content experts and authors identified additional sources. Those describing interdisciplinary palliative care (PC) and management of psychological/psychiatric distress in seriously ill AYAs, written in English, and completed in the U.S. between 2018–2023 were included. International citations were included if American literature was reviewed, or if authors described internationally developed PC standards by which American providers must practice. Clear and comprehensive data charting was completed by an independent reviewer, using a deductive approach with a standardized data-charting form developed prior to extraction.

**Results:** Sixty-five references met inclusion criteria. Psychologists most frequently published in the past 5 years regarding integration of their care into palliative teams. Authors wrote from eastern U.S., qualitatively studying the PC team in the oncology space. Of eight themes identified, barriers, facilitators, and interventions were most frequently reported.

**Conclusions:** Role delineation among PPC teams can be difficult in the management of psychological distress, due to lack of training and consistent collaboration models among cancer and non-cancer populations. Current literature highlights a large gap in psychological/psychiatric training. However, optimized pain control, routine screening of distress, open/honest/developmentally appropriate communication, and early advance care planning are interventions by which palliative providers can begin managing psychological distress in seriously ill AYAs. While the presence of psychologists and psychiatrists is widely variable among PPC teams, their expertise can vastly advance the field of PC, through collaboration, education, research, and advocacy.

**Keywords:** Interdisciplinary palliative care (interdisciplinary PC); pediatric palliative care (PPC); adolescents and young adults (AYAs); psychology; psychiatry

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## Introduction

### Background

Psychological distress is common in patients suffering from serious illness (1,2), and adolescents and young adults (AYAs) diagnosed with a serious illness are potentially the most vulnerable. Developmental risk factors associated with mental health comorbidity in AYAs are present in every aspect of their lives: socially, educationally, sexually, emotionally, relationally, spiritually, and culturally (3-9). Pediatric palliative care (PPC) teams are often consulted in these instances given their interdisciplinary approach to holistic management of complex patient scenarios. According to guidelines from the National Consensus Project (NCP) for Quality Palliative Care, and international standards for PPC, a systematic approach to the psychological and psychiatric aspects of care is expected by all palliative care (PC) programs, yet even regular screening of such distress continues to fall short, much less its holistic management and documentation (10-13). One reason for this shortcoming may be the wide variability in PC interdisciplinary teams (IDTs) across the nation. Most U.S. programs are not meeting recommended staffing standards of a core PPC team [physician (MD), advanced practice registered nurse (APRN), registered nurse (RN),

social worker (SW), and chaplain], and even more unlikely is the integration of psychology or psychiatry (22% and 4% of responding teams, respectively) (14). Additionally, psychological responsibilities across the PPC IDT remain nebulous, and overlap in many cases (2,15-28). Studies have shown that many members of IDTs are uncertain regarding their colleagues' baseline training (21,22,25), and therefore struggle to understand clinical boundaries within the IDT. Efforts have been made to specify standard competencies which could inform respective primary collegiate curricula, but few still encompass AYA-specific palliative skills (23,24,27,29-32). Overlap of roles can be problematic, for instance among chaplains, child life specialists and RNs who all have expertise in the recognition of symptoms in their distinct avenues of influence including spiritual/existential, developmental, and relational distress (19,21,33). Psychologists and SWs: both trained to understand how serious illness can affect an entire family unit; assess anticipatory grief and implement interventions such as identifying community resources; and are skilled in research and advocacy (17). Prescribing providers such as MDs, APRNs, and psychiatrists share the ability to assess for mental health disturbances such as anxiety and depression, and can prescribe subsequent medical treatment (28,34). This does not mean they all receive the same level of intensity in psychological training. Clearly a psychiatrist's collegiate curriculum more intently focuses on psychological issues throughout their entire program, whereas MDs and APRNs might have a course or two devoted to such studies. This may result in heavy reliance on the psychosocial expertise of SWs embedded in PPC teams when needs arise; however, SWs are not trained to prescribe. This is where collaboration becomes vital. However, it has been said that PPC is still a young discipline and, while larger academic pediatric centers have access to consultative-liaison services in psychiatry and psychology, collaboration models among specialty PC and subspecialties within the field remain in their infancy (35). Therefore, even the most resourced teams have difficulty delineating clinical margins within the vulnerable population of seriously ill AYAs experiencing comorbid psychological distress.

### Highlight box

#### Key findings

- Sixty-five references met criteria regarding palliative management of psychological distress in adolescents and young adults (AYAs) with serious illness.
- Eight themes included AYA vulnerability, barriers/facilitators to appropriate treatment, education/training of pediatric palliative care (PPC) team, patient/provider perspectives, and interventions.

#### What is known and what is new?

- AYAs present unique challenges, as normative development disrupted by terminal illness requires an interdisciplinary approach to care. National Consensus Project and international PPC standards include systematic management of psychological/psychiatric aspects of palliative care.
- Barriers exist in palliative management of psychological distress including lack of mental health training, routine screening, and collaboration among subspecialty teams.

#### What is the implication, and what should change now?

- Need for quantitative research guiding PPC practice, collaboration, and instructional design for PPC interdisciplinary team continuing education in the psychiatric management of vulnerable populations such as AYAs with serious illness.

### Rationale and knowledge gap

Differentiating between psychosocial, psychological, and psychiatric aspects of PC (2) is an important first step to understanding the knowledge gap (see *Table 1*). The term "psychological" will encompass psychological

**Table 1** Definitions

| Term          | Definition  | Palliative care  |
|---------------|---|--|
| Psychosocial  | Relating to the interrelation of social factors and individual thought and behavior | Typically delegated to LSWs  |
| Psychological | Relating to the mental and emotional state of a person                              | Expected to be recognized by RNs, APRNs, MDs, then followed up by supportive services such as counselors, psychologists  |
| Psychiatric   | Relating to mental illness or its treatment   | Models of collaborative care for mental illness are based on the availability of each region's resources (i.e., in large academic centers with ample resources, psychiatry is a subspecialty that palliative patients are referred to if mental illness becomes a concern) |

LSWs, licensed social workers; RNs, registered nurses; APRNs, advanced practice registered nurses; MDs, physicians.

and psychiatric services, and psychiatric distress where appropriate for the duration of this article.

Integration of psychologists and psychiatrists in PPC remains widely uncommon in the US. Therefore, PPC teams typically function without the involvement of psychological providers, are expected to manage psychological distress, yet continue to lack formal mental health professional training and continuing education opportunities (15,36,37). Understanding the aspects of the need as well as the overlap in delineation of roles and responsibilities among team members may inform more systematic management of psychological distress in AYAs with serious illness.

### Objectives

This paper aims to answer two questions: (I) What is the state of the evidence regarding the intersection of PPC and the management of psychological distress in AYAs with serious illness? (II) What is the state of current psychological learning opportunities for palliative providers across multiple disciplines? Given its multiple facets of inquiry, a scoping review was deemed the most appropriate method to systematically map the most current literature. Relevant key elements which conceptualize the review questions will be determined, such as discipline, geography, population, methodology, themes, and gaps in knowledge. This article is presented in accordance with the PRISMA-ScR reporting checklist (38) (available at <https://apm.amegroups.com/article/view/10.21037/apm-23-501/rc>).

### Methods

#### Preparation phase

Dividing between systematic versus scoping review was

accomplished by following a flow diagram from the University of Maryland, Baltimore's Health Sciences and Human Services Library (HSHSL) which can be found at <https://guides.hshsl.umaryland.edu/systematic/>. Given the needs for more than one research question, and to perform a basic qualitative content analysis for mapping, a scoping review format was deemed most appropriate. Discussion with an HSHSL librarian occurred via Zoom on May 31, 2023, where research questions were refined, relevant databases were chosen, and combinations of terms using respective Boolean and proximity search operators were chosen. The most recent search was executed on June 17, 2023. Immersion in the data quickly identified an existing population-concept-context framework (39), regarding the intersection of psychology and PPC, which informed the development of an associated scoping review protocol. The protocol was registered with the Center for Open Science on June 19, 2023, using the Open Science Framework (OSF) for optimal transparency and reproducibility of the review ([osf.io/fb48n](https://osf.io/fb48n)). Between June and July 2023, one reviewer searched five databases, GoogleScholar, and seven texts, as well as interviewed several content experts in PPC to ensure inclusion of all relevant records. Databases included Scopus, PubMed, Embase, PsycInfo, and Cumulated Index to Nursing and Allied Health Literature (CINAHL). Content experts who were interviewed were specifically chosen in order to represent the interdisciplinary PPC team including MDs, fellowship directors, nurse practitioners, SWs, pharmacists, chaplains, and consultative psychiatrists. Full electronic search strategies for each database are included in the registered OSF protocol, however an example from Embase is included here:

- (I) Used the basic search field, and unchecked the equivalent subjects option;
- (II) Used Emtree terms, truncation for psych\* and

**Table 2** Data charting codes

| General information | Key characteristics     | Population studied                | Context   | Outcomes        | Mapping checkboxes        |
|---------------------|-------------------------|-----------------------------------|---|-----------------|---------------------------|
| First author        | Paradigm/method         | Palliative team                   | Topic/focus/question                                  | Findings        | AYA vulnerability         |
| Date published      | Type of evidence source | Patient                           | Location of study/whether pediatric or adult facility | Future research | Palliative care role      |
| Title               |                         | Family                            | Sample size   | Limitations     | Professional competencies |
| Location of author  |                         | Discipline within palliative team | Other demographics                                    |                 | Standards/guidelines      |
|                     |                         | Age of patient(s)                 |   |                 | Provider perspective      |
|                     |                         | Gender                            |   |                 | Education/training        |
|                     |                         | Serious illness                   |   |                 | Interventions             |
|                     |                         |                                   |   |                 | Barriers/facilitators     |

AYA, adolescent and young adult.

educat\*, and proximity operators /exp and :ab,ti;

(III) ‘palliative’ AND mental:ab,ti AND disease:ab,ti AND [english]/lim AND ([adolescent]/lim OR [young adult]/lim) AND [2018-2023]/py;

(IV) (‘palliative’ OR ‘palliative therapy’/exp OR ‘palliative therapy’ OR ‘palliative nursing’/exp OR ‘palliative nursing’ OR ‘collaborative care team’/exp OR ‘collaborative care team’ OR ‘collaborative learning’/exp OR ‘collaborative learning’ OR ‘multidisciplinary team’/exp OR ‘multidisciplinary team’ OR ‘interdisciplinary education’/exp OR ‘interdisciplinary education’ OR ‘social work’/exp OR ‘social work’ OR ‘hospital subdivisions and components’/exp OR ‘hospital subdivisions and components’ OR ‘pharmacist’/exp OR ‘pharmacist’) AND (‘mental disease’:ab,ti OR ‘psychiatric treatment’:ab,ti) AND [english]/lim AND ([school]/lim OR [adolescent]/lim OR [young adult]/lim OR [middle aged]/lim) AND [2018-2023]/py.

Limiters for each database included date, age, and language: 2018–2023, AYAs ranging from 10–45 years of age, written in English. The North American age range for AYAs is defined as 15–39 years (3). However, not all databases offered a search limiter entitled “adolescents and/or young adults”. Rather, each database gave varying age ranges. Therefore, ages 10–45 were chosen to encompass all age range limiters offered among the collective databases, which include the desired 15–39 range.

Final sources described interdisciplinary PC and management of psychological/psychiatric distress in

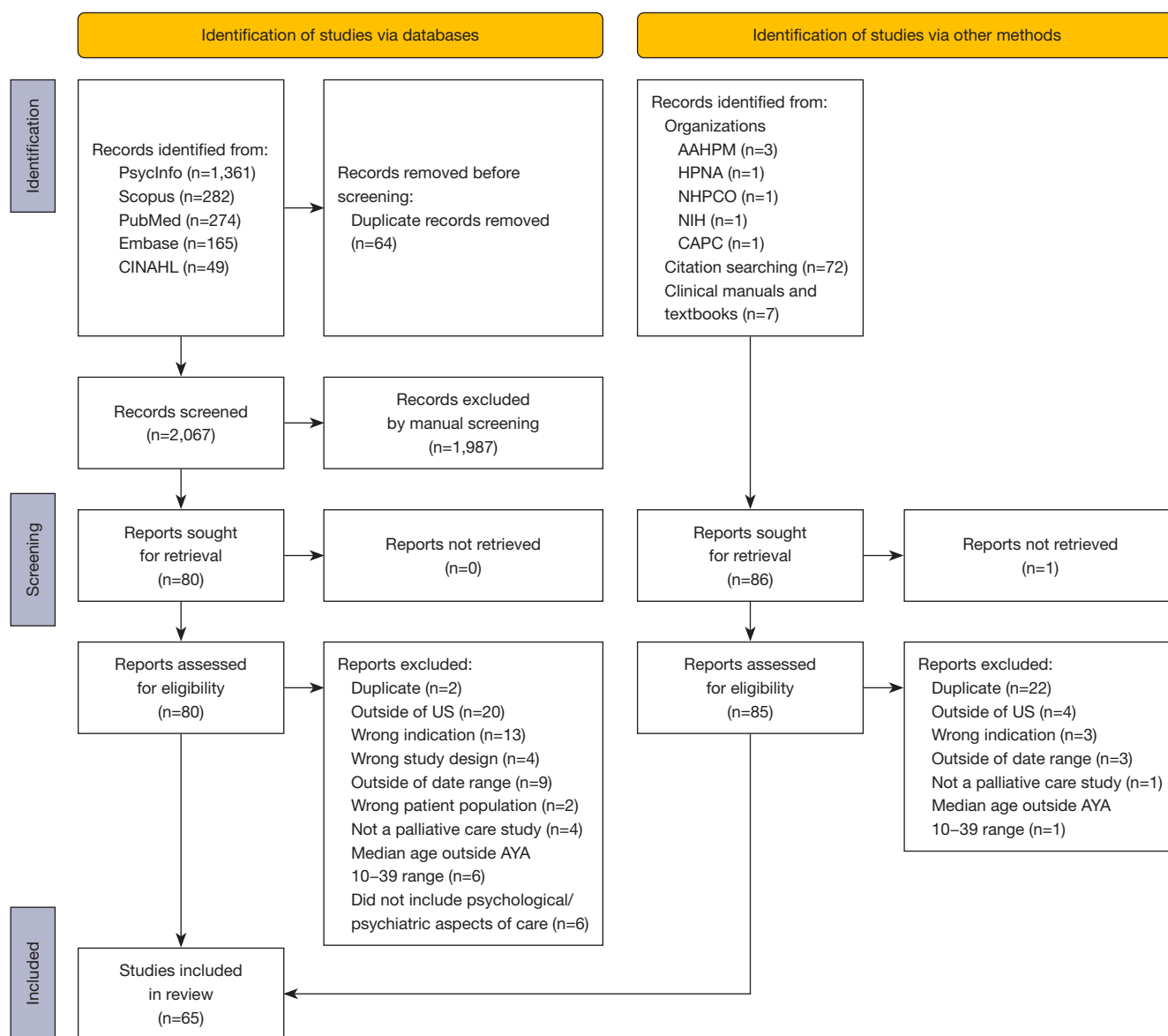
seriously ill AYAs, were written in English, and were completed in the U.S. between 2018–2023. International citations were included if American literature was reviewed, or if authors described internationally developed PC standards by which American providers must practice.

### Organization phase

The processes of extraction, analysis, and synthesis were completed using the Joanna Briggs Institute scoping review methodological approach (39) and were guided by the PRISMA checklist with Scoping Review extension. Title, abstract, and full text eligibility screening were completed systematically, by one reviewer, using the online Covidence screening tool. The same reviewer independently utilized Covidence software for data organization, using a deductive approach according to the set framework and codes (see *Table 2*) within the predetermined OSF protocol.

Mapping for barriers/facilitators was further subcategorized into nine options which included the following: (barriers) (I) attitudes/perceptions of mental health/AYAs, (II) lack of resources/access to psychological/psychiatric services, (III) lack of provider education/professional training, (IV) lack of provider management skills, and (facilitators) (V) psychological education in undergraduate/medical school, (VI) professional training/continuing education, (VII) interdisciplinary training for PC teams, (VIII) collaboration models, and (IX) integrated teams.

Data were exported as a .csv file from Covidence into Microsoft Excel and compiled into a table available at



**Figure 1** PRISMA flow diagram. CINAHL, Cumulated Index to Nursing and Allied Health Literature; AAHPM, American Academy of Hospice and Palliative Medicine; HPNA, Hospice and Palliative Nurses Association; NHPCO, National Hospice and Palliative Care Organization; NIH, National Institutes of Health; CAPC, Center to Advance Palliative Care; AYA, adolescent and young adult.

<https://cdn.amegroups.cn/static/public/apm-23-501-1.pdf>. However, given the large amount of information extracted, creative approaches were taken to convey results. Data within excel were recoded into numerical values for sums, imported into a user-friendly business intelligence software called Tableau, and analyzed in charts and graphs according to research questions. Results will be presented in figures according to the relevant key elements which conceptualize

the review questions, as previously listed.

## Results

A total of 2,217 citations were identified from electronic databases, reference trails, and clinical manuals. After duplicates were removed, 2,153 references were screened per title and abstract, and 1,987 sources were excluded.



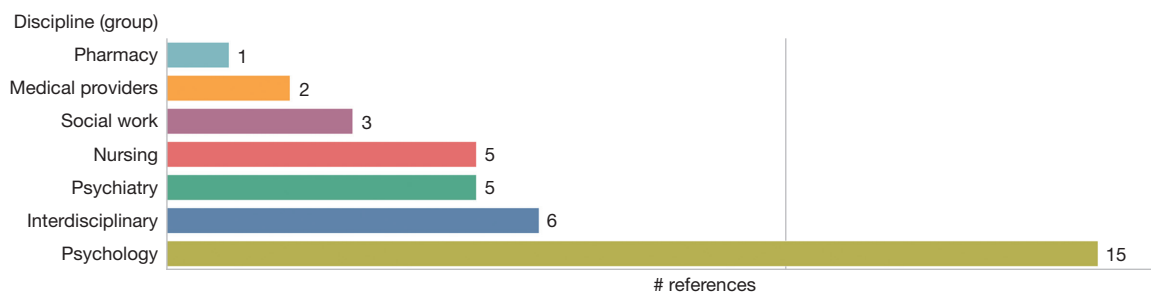


Figure 2 Publications per discipline bar graph.



Figure 3 Publications per geographical location map.

One book chapter was unable to be retrieved, leaving 165 full texts to be screened for eligibility, of which 65 met final inclusion criteria (see PRISMA flow diagram in *Figure 1* and table available at <https://cdn.amegroups.com/static/public/apm-23-501-1.pdf>). Seven sources found in reference trails were outside of the date range yet were included given their current relevance to the field.

#### *Who's writing?*

Of the authors that specified their discipline ( $n=37$ ), 40% of the included references were written by authors from the field of psychology, followed by the IDT, psychiatry, nursing, social work, medical providers, and pharmacy (see *Figure 2*).

Most literature was written in the eastern region of

the United States, more specifically authors from Boston Children's Hospital and Dana-Farber Cancer Institute in Massachusetts (see *Figure 3*).

#### *Who's being studied?*

Sixty-eight percent reported on the PC team population, while the rest focused on the patient and family (26% and 6%, respectively) (see *Figure 4*).

A total of 22 references described cases of AYAs with specified serious illness, and only two studied non-cancer diagnoses (see *Figure 5*).

Of those same 22 studies, very few specified genders ( $n=5$ ), and four were based on female cancers. The male study was a qualitative case study based on one male oncology patient.

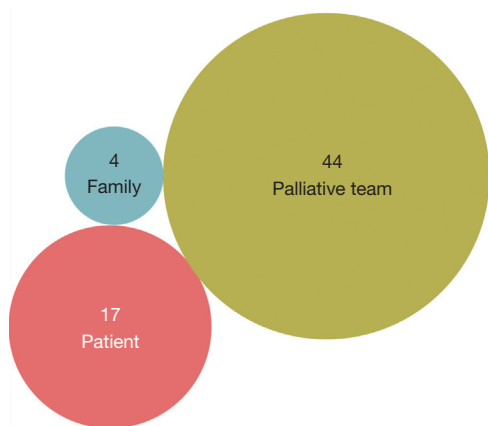


Figure 4 Publications per population bubble chart.

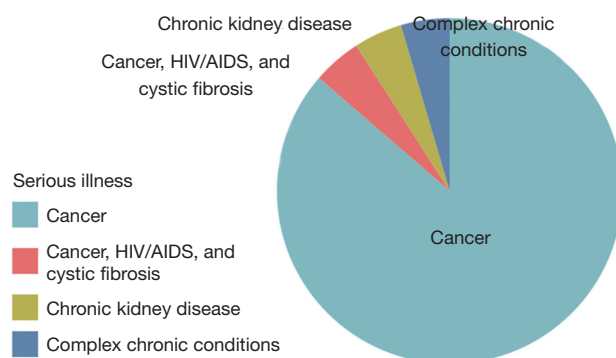


Figure 5 Publications per disease pie graph. HIV, human immunodeficiency virus; AIDS, acquired immunodeficiency syndrome.

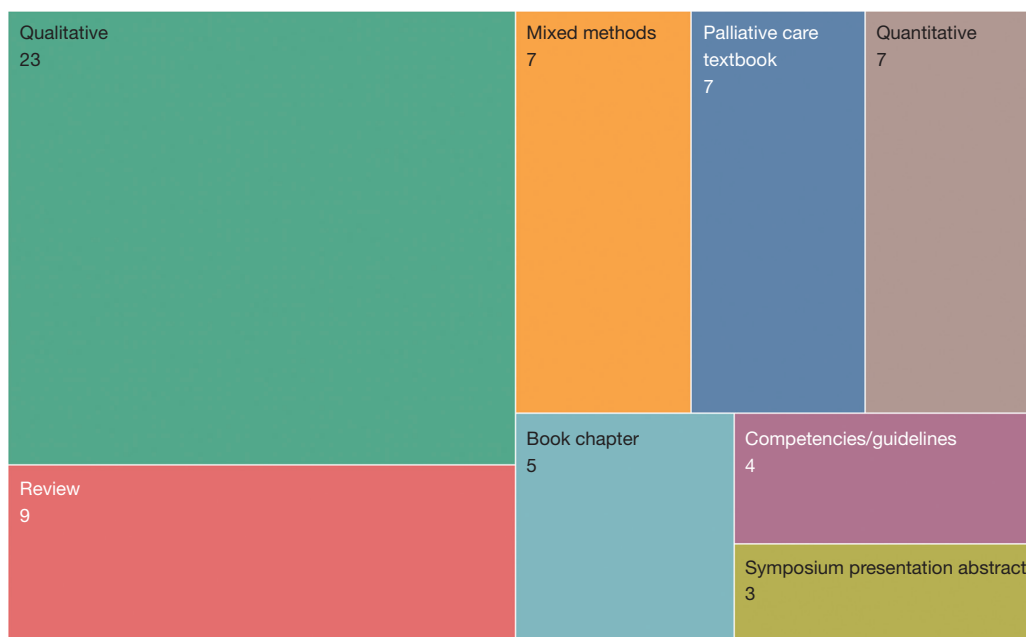


Figure 6 Publications per methodology tree map.

*How's it being written?*

The following tree map displays data in nested rectangles, using dimensions to define the hierarchy, quantity, and patterns among extracted data according to methods of study (39) (see Figure 6). Thirty-five percent, the majority of included literature, used qualitative methods (23 total references). However, professional practice competencies and guidelines only represented 6% of the literature, and symposia presentations were even fewer at only 4% (total of four references and three references, respectively).

*What's being written?*

Eight total themes were noted throughout the included literature, many overlapping in each reference. For example, a single study discussed educational background and competencies of a discipline, then concluded with lack of training as a barrier in PC; therefore, the single reference was coded as covering multiple themes (see Figure 7). All disciplines, and over half of all included references, concluded with presenting the need for more education in the realm of managing comorbid distress in AYAs with

serious illness (see *Figure 8*).

Interventions most repeated in the literature were early discussion of goals and advance care planning (ACP). This included fostering shared decision-making and honest communication between provider, patient, and family; regular assessment of psychological distress in AYAs; and

optimized pain control as an eliminating factor contributing to psychological distress (see *Figure 9*).

Both psychology and the PPC IDT wrote about regular screening and ACP. While optimized pain control was more often addressed by the PPC IDT, counseling or talk-therapy (referred to as psychotherapy), cognitive behavioral therapy (CBT) and other psychological interventions were more commonly discussed by the psychology and psychiatry groups (see *Figure 10*).

Multiple barriers to managing psychological distress in AYAs with serious illness were mentioned in the included articles. Lack of professional education and mid-career training in both psychiatric and PC disciplines posed the largest barrier to the management of distress, followed by lack of appropriate management skills by PC providers; lack of resources or patient access to psychology/psychiatry services; and finally poor perceptions and attitudes surrounding mental health in AYAs (see *Figure 11*).

Facilitators to the provision of adequate psychological support to seriously ill AYAs were subcategorized to include more professional training, collaboration among psychology/psychiatry and PPC teams, increased availability of IDT learning opportunities, the integration of psychology/psychiatry services into PPC teams, and psychiatric education (both PC education in psychology programs and psychological education in PC programs).



Figure 7 Themes tree map. PC, palliative care.

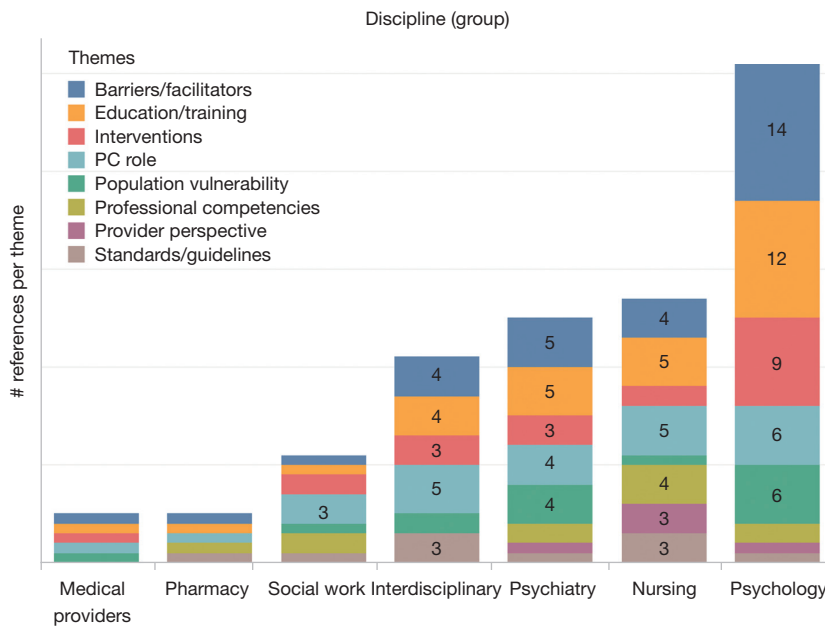
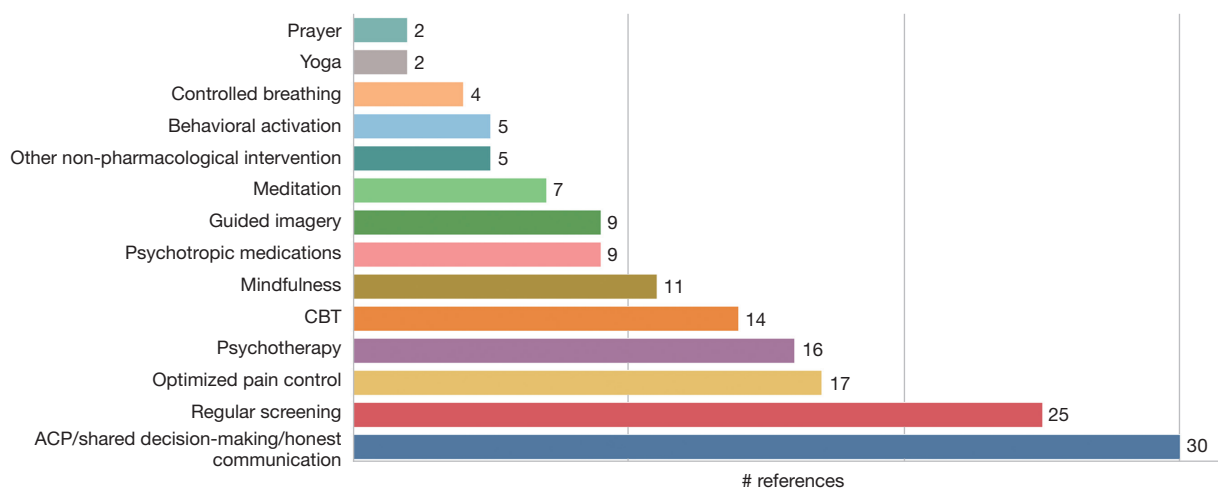
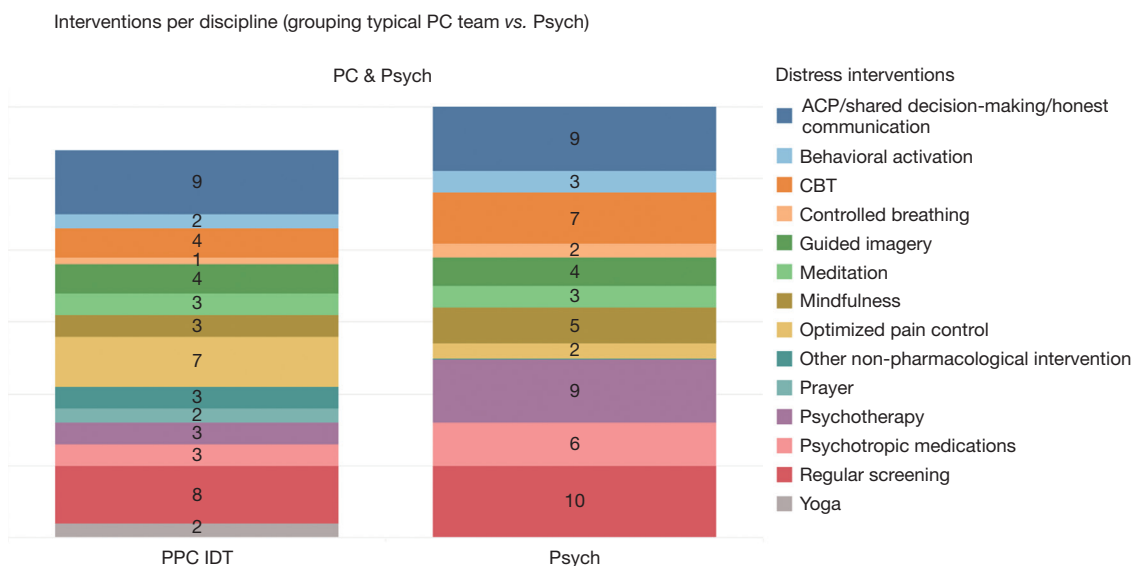


Figure 8 Themes per discipline stacked-bar chart. PC, palliative care.





**Figure 9** Interventions bar graph. CBT, cognitive behavioral therapy; ACP, advance care planning.



**Figure 10** Interventions per discipline stacked-bar chart. PC, palliative care; Psych, psychology/psychiatry; ACP, advance care planning; CBT, cognitive behavioral therapy; PPC IDT, pediatric palliative care interdisciplinary team.

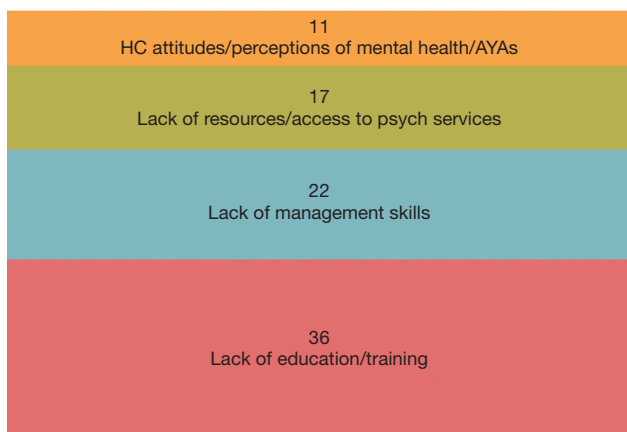
Fairly even frequency distributions were noted in facilitators among existing models for professional and interdisciplinary training, as well as collaboration and integration between psychology/psychiatry and PPC teams (see *Figure 12*).

**Discussion**

*Key findings and implications*

In this scoping review, 58 primary references were identified which addressed the roles, responsibilities, and training

of PPC providers in the management of psychological distress in AYAs with serious illness. Given the wide range of disciplines covered in this review, and the need to include seven additional resources which were out of the specified date range, it is clear there remains a gap in specific guidance regarding this vulnerable population. Findings largely focus on the PC team and barriers which prevent holistic management of distress in AYAs with cancer diagnoses. Tailoring palliative interventions according to developmental and cultural influences for



**Figure 11** Barriers tree map. HC, healthcare; AYAs, adolescents and young adults; psych, psychological/psychiatric.



**Figure 12** Facilitators tree map. Psych, psychological/psychiatric; IDT, interdisciplinary team.

the AYA population requires a significant amount of time and understanding. Current literature highlights the importance of AYAs being treated in pediatric institutions, where care plans are created surrounding normative developmental needs of AYAs; however professional educational opportunities specific to the vulnerable AYA with serious illness continues to be insufficient in adult and pediatric institutions alike. Clinical competence suffers due to the absence of training, limited access to subspecialty consultative services, lack of delineation among overlapping roles, and lack of standardized collaborative models. Feasible PC-specific interventions which help to eliminate risk factors for distress were found, and mainly included early and honest communication and ACP, routine

distress screening, and optimized pain control. These findings could be especially helpful for the palliative MD, advanced practice provider, nurse, and SW. Finally, two recommendations for systemic issues related to clarifying the intersection of psychiatry and PPC were consistently highlighted in the literature: PPC/psychology/psychiatry collaborative models and continuing interdisciplinary education for PPC providers; both of which will promote the systematic management of psychological distress in AYAs with serious illness, therefore fulfilling the national and international expectations for quality PPC. The breadth of information this scoping review brings will promote further PPC research in vulnerable populations, as well as educational initiatives specific to AYAs experiencing psychological distress.

### Limitations

Only three citations (8,9,40) reported on racial disparities that exist in addition to the already-vulnerable AYA. Additionally, non-cancer complex chronic illnesses were not well represented in the literature (n=2). Furthermore, oncology standards recommend integrated psychological support within oncology teams, and subsequently have their own psychology services. The included literature rarely addressed this aspect of care, and how PPC IDTs fit within that model. Finally, while the need for rigor in all aspects of human science research is understood, and multiple reviewers decreases the risk for bias, this publication served as a portion of a larger dissertation completed through the University of Maryland, Baltimore. As a result, this scoping review was completed and written according to the requirements of the university necessitating sole authorship.

### Actions needed

To realize NCP guidelines' third domain and satisfy the international PPC guidelines' expectations for psychological aspects of care, there is a universal need for knowledge-sharing between psychology and PPC. A globally accessible systematic approach to interdisciplinary skill training, geared toward mid-career adult learners, will optimize care for seriously ill AYAs experiencing comorbid psychological symptoms.

### Conclusions

AYAs with serious illness are a unique population due to

their rapidly transitioning stages of normative development during a life-limiting illness. While a scoping review is not meant to inform practice or policy, this review has identified several gaps which should guide future research with respect to the research questions at hand.

***What is the state of the evidence regarding the intersection of PPC and the management of psychological distress in AYAs with serious illness?***

Psychologists from large academic pediatric centers are responsible for most included literature, which is methodologically qualitative. References from 2018–2023 focus largely on the need for role delineation and collaboration among the interdisciplinary PPC team and consultative psychiatry, mainly among the AYA cancer population. While standardized practice will be difficult to attain due to the variable makeup of PPC IDTs and availability of mental health resources across the nation, PPC providers can begin by routinely assessing for psychological distress and being open to early ACP with AYAs facing serious diagnoses. Quantitative studies covering the feasibility and efficacy of collaborative models among psychology/psychiatry and PPC IDT could inform best practices in well-resourced areas, which could lead to the advocacy of policy change requiring integration of psychological expertise into PPC teams who serve in less-resourced regions. More information is needed in PPC practices among racially diverse areas of the country, and studies should focus on the patient and family. Additionally, reviews are needed regarding the validity and reliability of distress screening in AYAs with serious illness in subpopulations that are most at risk.

***What is the state of current psychological learning opportunities for palliative providers across multiple disciplines?***

Primary education curricula which include psychological training heavily depend on the discipline track chosen in undergraduate and graduate programs. While baseline education varies widely, all professionals within the PPC team are expected to be aware of psychological distress to some extent and possess the ability to communicate and document concerns. Efforts have been made to provide courses specific to PC in medical, nursing, pharmacy, psychology/psychiatry, and social work programs, and some competency guidelines even require such training. However,

to the best of our knowledge and searching through this scoping review, none are specific to AYAs. Efforts have also been made to provide one to two-week psychiatric rotations in clinical PPC fellowships, but most remain elective. National organizations such as the American Academy of Hospice and Palliative Medicine continue to include presentations at annual assemblies, and plan to offer a one-day clinical course on essential psychiatric skills for palliative providers in November 2023.

Interdisciplinary continuing education and online learning opportunities tailored to mid-career pediatric palliative professionals will help delineate roles among overlapping disciplines in the management of comorbid psychological distress in AYAs with a life-limiting illness. This can inform best practices in the treatment of AYAs. This review advocates for knowledge-sharing among disciplines as an evolving educational approach to understanding roles and responsibilities among vulnerable AYA populations in PPC.

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*Peer Review File:* Available at <https://apm.amegroupp.com/article/view/10.21037/apm-23-501/prf>

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