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## A Scoping Review of the Experiences of Adolescents and Young Adults in the ICU, Their Family Members, and Their Health Care Team

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# A Scoping Review of the Experiences of Adolescents and Young Adults in the ICU, Their Family Members, and Their Health Care Team

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## Keywords

Adolescents, Young adults, Intensive care unit, Experiences, Family, Parents

## Key points

- Adolescents and young adults (AYAs) with critical illness and their caregivers may have distinct needs and distress that stem from their developmental life stage.
- Evidence about the experiences of AYAs in the ICU is limited, and specific literature about young adults in the ICU was nearly nonexistent.
- Health care professionals need to involve AYAs and their family members in decision making and consider ways to offer developmentally tailored resources in the ICU.
- There are opportunities to improve serious illness communication skills and advance care planning for AYAs who require ICU care.

## Introduction

*Adolescent and young adult* (AYA) is a term that has emerged in health care to specify a unique developmental period and population. AYAs are in a transitional period between childhood and mature adulthood, resulting in specific health care needs and experiences that are distinct from younger children and older adults. Health care providers are challenged to provide age-specific care for AYAs and their families across specialties to improve AYAs' health outcomes. Although there is no consensus about the age parameters for AYAs, the broadest definition defines AYAs as individuals between the ages of 15 years old and 39 years old.<sup>1</sup>

Adolescence/young adulthood is a dynamic period of development, with transitional milestones related to becoming independent from parents, advancing toward career and work goals, choosing life partners, and establishing families of their own.<sup>2</sup> This vulnerable period also is characterized by risk-taking behaviors and feelings of invincibility.<sup>3</sup> Age-related health disparities are evident in this population due to greater violence and injury, being uninsured, not having a primary care provider, and delays in seeking health care, often leading to poorer health care outcomes.<sup>4</sup> The leading causes of morbidity and mortality in this age group include unintentional injury, homicide, suicide, cancer, and heart disease.<sup>5</sup>

ICU admissions for AYAs are not uncommon and may be due to injury, malignancy, substance abuse, or exacerbations and complications related to pediatric-onset chronic illnesses.<sup>6</sup> AYAs, depending on their age, may be cared for in either an adult ICU or pediatric ICU. In a recent search of the Vizient Clinical Database pre-COVID-19, the authors found that AYAs (individuals younger than 39 years old) account for approximately 15.3% of admissions to adult ICUs.<sup>7</sup> In adult ICUs, a majority of patients are 50 years or older,<sup>8</sup> whereas in a pediatric ICU, a majority of patients are under 10 years of age.<sup>9</sup> The developmental and supportive needs of AYAs differ from those of the populations typically served in adult and pediatric ICUs.

The limited AYA-related critical care research suggests some important trends in AYA ICU care.<sup>6,10</sup> In 1 study that examined AYA ICU admissions, in comparison to older adults, AYA patients more often were male, more often were African American/black, and had shorter median lengths of stays that were largely related to risk-taking behaviors and pediatric chronic illness.<sup>6</sup> In a sample of 705 AYA patients with cancer (ages 15–29 years), 21% had an ICU stay, 75% received high-intensity end-of-life care, 65% died in an acute care setting, and only 23%

received hospice care.<sup>11</sup> The ICU providers may offer AYA patients aggressive ICU care based on their assumption that these younger patients would benefit from life-saving and sustaining treatments.<sup>12</sup>

To fully understand the needs and improve care of the AYA population during an ICU stay, the experiences of the ICU team caring for AYAs also must be comprehended. Caring for an adolescent or young adult in a pediatric ICU may be challenging for a health care professional who works more commonly with younger children. Similarly, caring for an AYA in an adult ICU may pose challenges to health care professionals who are accustomed to working with older adults. ICU clinicians report more distress when caring for AYAs than when caring for critically ill children or adults.<sup>13</sup> Efforts to increase health care professionals' knowledge and awareness of the unique needs of AYA populations could improve the clinical practice of those caring for AYAs in both pediatric KICU and adult ICU settings. The authors' research team held in-depth discussions about their clinical experiences with AYAs in the ICU setting. To frame this scoping review, the authors describe a case of an AYA patient that illustrates unique critical illness challenges in this population. Some details of this case have been changed to protect the patient's anonymity.

## Exemplar case

Violet, 28 years old, was admitted to the adult ICU and experienced ventilator-dependent chronic respiratory failure, refractory pain, anxiety, delirium, multisystem organ failure, and malnutrition. Despite escalation of life-prolonging interventions, Violet experienced progressive medical decline over 9 months and ultimately died from complications of her underlying illness. Violet was not married, had no designated health care proxy, and had no advanced directive. Violet voiced her desire to live for her young children, and, when she was given options, chose life-supportive interventions. Because Violet had not designated a health care power of attorney (HCPOA), it was unclear whether the appropriate surrogate decision maker (SDM) should be her mother (Donna) or her partner, the father of her young children. Although Violet was not close to her mother, as her condition worsened, Donna stepped in and became her sole decision maker. The team had concerns about Donna's well-being and her ability to cope with her daughter's serious illness and imminent death. There was ongoing conflict among the health care team about changing goals of care to prevent unnecessary suffering. The team experienced moral distress about how Violet's care unfolded, and this distress was compounded by her young age.

As the research team reconsidered Violet's case, the authors wondered if unique factors, such as her young adult status and lack of appointed SDM, may have contributed to our concerns about her suffering and long length of stay in the ICU. Did the authors have different expectations of recovery for this young adult patient versus an older adult with comorbidities? Are there differences in the authors' experiences as health care professionals caring for younger patients versus older patients? Did the authors meet the needs of this young adult patient and her parent? What about her young children, significant other, and extended family members and friends? These lingering questions led the team to explore through a scoping review what is known about the serious illness experiences of the adolescent and young adult population in the ICU setting from the perspective of 3 key stakeholders: patients, family members, and health care professionals.

There have been multiple calls to address the palliative care needs of AYAs.<sup>14,15</sup> Given gaps in the integration of palliative care in critical care environments for both pediatric ICUs and adult-focused ICUs, however, studying the experiences of AYAs in ICUs, their family members, and their ICU team may uncover opportunities to better address the developmental needs of AYAs with serious illnesses. Therefore, the purpose of our scoping review is to describe the extent, range, and nature of existing literature pertaining to AYA experiences in the ICU setting and identify key gaps to guide future research specific to this population and setting.

## Methods

A scoping review is the method of choice when a topic has not previously been reviewed extensively.<sup>16</sup> This scoping review was guided by the methodological framework of Arksey and O'Malley<sup>16</sup> and the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist.<sup>17</sup> Arksey and O'Malley (2005) describe a 6-step method that begins with identification of research question(s) and proceeds with obtaining relevant studies, developing criteria for study selection, charting the data, and summarizing and reporting the results. Research questions guide the build of the search.<sup>16</sup> The authors' research questions were as follows:

1. What are the experiences of AYA patients and their families in the ICU?
2. What are the experiences and perspectives of the health care professionals who care for AYA patients and their families in the ICU?
3. What are similarities and differences among the AYA stakeholder perspectives: patient, family members and healthcare professionals?

The search included adult and pediatric ICUs and all specialty ICUs with the exception of neonatal. AYAs were defined as individuals from 15 years of age to 39 years of age.<sup>1</sup> Although the age range for AYAs has not been defined in health care literature with consistency, AYA generally is defined based on the unique developmental needs that fit neither into the adult nor pediatric definitions. The World Health Organization (WHO) refers to "young people" as AYAs from 10 years of age to 24 years of age. The Society for Adolescent Health and Medicine uses the range of 18 years to 25 years as the definition for young adults.<sup>4</sup> The National Cancer Institute (NCI) defines AYAs as the group of patients between 15 years of age and 39 years of age based on the distinctive epidemiology and biology of cancers that occur in these patients. Because cancer remains one of the leading causes of death for the AYA population,<sup>5,18</sup> in this scoping review, the authors adopted the definition of AYA used by the NCI.

For the purposes of this review, domains of experiences were defined as psychological, spiritual, physical, emotional, financial, quality of life, well-being, communication, conflict, satisfaction, empathy, respect, and distress. To be included, a study had to examine 1 or more experience domains. Post-hospitalization studies were included if their research question was focused on the ICU experience (post-ICU recovery excluded). Only studies were included in which AYAs were a specific sample, if the mean age of the sample was between 15 years and 39 years or 1 majority of the sample was in that age range. Studies were excluded that did not report experiences, recall, or memories; reviews, case reports, editorials or opinion pieces; and dissertations. Studies were also excluded that were not written in the English language. The authors limited the search to articles published from 2010 to 2020, because AYA is a newer term in the literature.

The authors searched CINAHL, Ovid Medline, Scopus, and PsycArticles in May 2020. Search terms and complete search strategy for CINAHL are found in Fig. 1. In the first phase of the screening process, 3 researchers (NM, JG, and JE) independently reviewed titles and abstracts for inclusion. In the full-text phase of the process, 5 team members (NM, JG, JE, AB, and SM) independently reviewed full text articles and then discussed disagreements about inclusion until consensus (majority) was reached. Once the authors determined the articles that would be included in the scoping review, the following information was extracted from each study: design, sample characteristics, setting, measures, and results specific to the AYA experience in the ICU. Three members of the team (NM, JE, and JG) worked to synthesize and collate these data into an evidence table (Table 1). After the evidence table was complete, 3 additional team members (JP, SM, and AB) reviewed the findings to verify data extraction.

(adolescen• OR ((MH "Adolescent Health Services")) OR ((MH "Adolescent Medicine")) OR teen• OR {{MH "Young Adult"}} OR {teenage• AND {young AND adult}} OR {(young AND adult\*)} OR {(young AND person\*)} OR ((young AND people)) OR AVA OR ((young AND patient\*)) OR ((young AND wom\*n)) OR ((young AND female\*)) OR ((young AND m\*n)) OR youngster\* OR youth OR ((emerging AND adult)) OR ((early AND adulthood)) OR ((pre AND teen\*)) OR preteen\* OR ("pre adolescen\*") OR preadolescenc\* OR {{MH "Minors {Legal}"}} OR minor\*) AND {{{MH "Intensive Care Units+"} OR "intensive care units"} OR ((MH "Intensive Care Units, Neonatal")) OR ((MH "Intensive Care Units, Pediatric+")} OR ((MH "Neonatal Intensive Care Nursing")) OR {{MH "Critical Care+"}} OR (intensive AND care AND unit) OR ICU) AND ("health communication") OR {{MH "Decision Making+"}} OR interact• OR talk OR conversation\* OR discuss\* OR empathy OR ((decision AND making)) OR ("shared decision-making") OR experience OR ((MH "Professional-Pati~nt Relations+")) OR ((MH "Anxiety+")) OR ((MH "Stress, Psychological+")) OR {{MH "Fear+"}})

Fig. 1. Full search strategy from CINAHL.

Table 1. Table of findings for scoping review

Author, Year Country	Study Aims and Framework	Study Design	Patient, Family, and Health Care Professional Perspectives and Characteristics	Setting	Measures and Analysis	Findings Related to Experience/delivery of Care for Adolescents and Young Adults
Johansson (2014) <sup>23</sup> Sweden	To explore the emotional responses of family members of a young adult patient in the ICU No framework (inductive approach)	Qualitative/descriptive, case study, secondary data analysis	Family perspective Mother and father, both middle aged *Patient was a 19-year-old woman in ICU for 5 wk with pneumonia	Adult ICU	One-on-one interviews with mother and father (separately) with guiding question Hermeneutic analysis (Gadamer approach)	Six themes related to parent emotions were uncovered: 1. Feelings of uncertainty: daughter's survival and quality of life 2. Feelings of abandonment: when health care team did not allow parents by daughter's side 3. Feelings of desertion from the loved one: guilt related to inability to fulfill moral obligations to daughter 4. Feelings of being close to deathbed: processing potential death of daughter 5. Feelings of being in a no-man's land: being in disequilibrium with family roles and routine 6. Feelings of attachment: love for daughter and need to be close Other key findings: parents' extreme emotional responses—existential distress and



						suffering; strong need to “be with” young daughter
Maxim et al. (2019) <sup>20</sup> United States	To describe family satisfaction in a trauma and surgical ICU No framework	Descriptive	Family perspective N = 103, 75% female Median age of family member = 41 (IQR = 29–56); 45% of family sample had been in ICU in past; race and family relationship not reported but sample included both English and Spanish speaking family members. * These family members represented 88 patients: 71.6% male and 83.7% trauma injury; median age = 37.5 y; median ICU stay: 11 d	Adult ICU Trauma-surgical ICU in level I trauma center	Family satisfaction (FS-ICU 24) Demographics Mean and SD for each item and composite score	Overall high family satisfaction (M = 80.1/100; SD = 26.7) Less satisfaction surrounding items related to amount of care provided (M = 64.1; SD = 36.8), atmosphere of waiting room (M = 64.8, SD = 33.3) communication between physicians and family (mean = 70.7; SD = 29.5) Open-ended comments: need for better interpreter services, accommodations for families, and more communication with physicians * Results not specific to AYAs (included older adults)
Needle et al. (2019) <sup>12</sup> United States	To explore the perspective of physicians in pediatric ICUs and hematopoietic stem cell	Qualitative/descriptive	HCP perspective N = 15 physicians (4 HSCT attendings; 11 pediatric ICU attendings and fellows)	Pediatric ICU Large HSCT program	3 focus groups with interview guide Content analysis	Two themes uncovered: 1. The temporal context of advance care planning and decision-making: HSCT attendings: see AYA patients throughout trajectory of illness

	<p>transplant (HSCT) related to adolescent and young adult advance care planning and end-of-life decision making No framework (inductive approach)</p>		<p>Mean age = 40 y (29–62 y); mean years for physician practice = 10 y (1–31 y) *The HSCT program served patients from birth to 26 y of age; focus of study was on adolescents and young adults undergoing HSCT</p>			<p>from diagnosis to death or cure. Pediatric ICU physicians: only see those with serious complications. Both groups thought conversations should occur when patients are well enough to express their values and goals as decisions about life-sustaining treatment can be different when well vs ill.</p> <p>2. The limitations of pediatric advance care planning: embodied knowing (feeling and understanding) and by witnessing; the impact of clinical cascades in a new normal of aggressive, life-sustaining care; balancing AYA autonomy with capacity to make decisions; and different ways of understanding for providers, patients, and their families</p> <p>Other key findings:</p> <ul style="list-style-type: none"> <li>• Physicians felt obligated to offer life-sustaining treatment but that AYA patients may not fully understand options and consequences.</li> <li>• Patients and families may learn consequences through experience of care (may not be fully informed).</li> <li>•</li> </ul>
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						<p>Social media plays a role in patient and family decisions through communication with others in similar situations.</p> <ul style="list-style-type: none"> <li>• Physicians shared difficult emotions and felt they did not always full disclose limits of medicine because they had to be confident patient would not survive before discussing death.</li> <li>• Physicians base decisions on science and data; families base decisions on religious, cultural, and social constructs and how they process provided information (this can lead to conflicts regarding end of life care).</li> </ul>
Robert et al. (2012) <sup>22</sup> United States	To understand the needs and experiences of bereaved parents whose child received care at a comprehensive cancer center and determine their expectations of palliative care and how palliative care can be improved. No framework	Qualitative, descriptive	Family perspective 14 Parents of children who died a minimum of 1 y prior to participation (and child was at least 10 y of age at time of death) Mean age of parents = 51 y (SD = 6); 10 parents were white; 3 were Mexican; and 1 was Arab	Pediatric ICU and acute care	3 Focus groups using interview guide that was developed from the literature Content analysis	Results specific to pediatric ICU: Bereaved family members reported <ol style="list-style-type: none"> <li>1. Receiving specialized attention with high support</li> <li>2. Barriers to being with the child (eg, visitation rules, no chairs, no resources)</li> <li>3. Feeling unclear when to return to patient from waiting room</li> <li>4. Need for staff to accommodate presence of younger siblings</li> <li>5.</li> </ol>

	(inductive approach)		American *These parents represented 9 children (6 boys and 3 girls) with a mean age of 15 y (SD = 3)			Lack of communication/information Other key findings related to family members' perspectives: <ul style="list-style-type: none"> <li>• Separation from child profoundly distressing</li> <li>• Need for more consistent providers</li> <li>• Parents wanted child to have some control in end-of-life discussions; must be tailored to needs</li> <li>• Some providers avoided discussions about death</li> </ul> *Not AYA specific—included younger children
Rusinova et al. (2014) <sup>19</sup> Czech Republic and Slovak Republic	To assess the prevalence of symptoms of anxiety and depression among family members of ICU patients; family understanding of patient condition; and identify family needs and satisfaction No framework	Descriptive/correlational	Family perspective 405 family members; median age = 41.5 y (16–87); 71.5% female; race not reported; 23% spouse; 48% parents; 15% sibling *These family members represented 293 patients with a median	17 Adult ICUs 5 Pediatric ICUs	Hospital Anxiety and Depression Scale (HADS) Critical Care Family Needs Inventory (CCFNI) Researcher developed questionnaire on information and support received Structured interview to elicit comprehension	The age of the patient was inversely associated with depression scores. Family members of younger patients had higher scores for depression symptoms on HADS). Family members of patients in PICUs had better comprehension of patient diagnosis than family members of patients cared for in adult ICUs (OR = 1.688, CI 1.17–2.32), <i>P</i> = .008 No differences found for anxiety and depression symptoms in family members

			age = 39 y; mean ICU LOS = 13 d		of information provided by ICU staff Descriptive statistics, correlations, multivariate regression	based on the patient's care in adult vs pediatric ICU 61.2% of family members did not understand the patient's diagnosis, features of treatment or prognosis. 27.4% wanted help from a psychologist. 17.4% received contradictory information *Results not specific to AYAs (included older adults and children)
Sevinç et al. (2016) <sup>24</sup> Turkey	To describe the experiences of family members of patients in the ICU No framework (inductive approach)	Qualitative/descriptive	Family perspective N = 30; 25 males and 5 females, mean age = 33 y All were Syrian; 9 were brothers, 7 parents, 4 sons, 4 uncles, 3 spouses, and 3 of other type of relationship *These family members represented 30 patients with a mean age of 33 (SD = 11.42)	Adult ICU	One-on-one semistructured interviews Demographic questionnaire Thematic analysis	There were 6 themes about family experiences: 1. Communication-related difficulties 2. Difficulties receiving information regarding the patient's condition 3. Difficulties meeting personal needs 4. Difficulties receiving social support from other family members 5. Unmet expectations from nurses and hospital administration * Results not specific to AYAs (included older adults)
Villadsen et al.	To describe the impact of a	Qualitative/descriptive	Patient perspective	Adult and pediatric	One-on-one interviews using	Three themes were uncovered: 1.

(2015) <sup>26</sup> Denmark	social-pedagogical intervention by giving adolescents the chance to talk about their experiences No framework		N = 7 adolescents suffering from acute or chronic critical illness Ages ranged from 14 to 20 y; LOS at time of interview ranged from 14 d to 9 mo	wards; some patients were in the ICU during hospitalization (unclear how many) *Not specific to ICUs (included acute care unit experiences)	an interview guide Content analysis	Recreation: adolescents appreciated physical activities offered by social educator; they valued their relationship with social educator because nurses were too busy; physicians reduced them to a diagnosis; and psychologists were associated with mental illness. 2. Structure, participation and motivation: adolescents looked forward to working with the social educator was and sessions gave them control to make decisions. This control led to motivation for their treatment and to exercise. 3. Friends and social network: It was difficult for these adolescents to keep in touch with their friends and share experiences. Working with social educator gave them something to discuss with their friends. The intervention also facilitated socialization with other hospitalized adolescents to promote normalcy. *Other key finding: adolescents talked about the importance of “getting a break” from illness, treatment, the hospital, and their overprotective parents.
Wood et al.	To identify factors that are	Qualitative/descriptive	Patient and family member	Adult and pediatric ICUs	Dyadic interviews	Two factors were identified that affected the ICU experience:

<p>(2018)<sup>21</sup> United Kingdom</p>	<p>important to adolescents and their families during their ICU and high dependency unit (HDU) stay No framework (inductive)</p>		<p>perspective (dyads of child and mother) There were 9 adolescents (mean age 15.9 y, range of 14–19); 4 were cared for in an adult ICU and 5 in pediatric ICUs 9 mothers participated, demographics not reported 8 mother/child dyads included; 1 interview was with the mother alone.</p>	<p>(representing 4 hospitals)</p>	<p>Framework approach to analysis: familiarization, identifying thematic framework, indexing, charting, mapping and interpretation</p>	<ol style="list-style-type: none"> <li>1. Environment: some adolescents discussed that they were surrounded by very old people whereas others said activities on the pediatric ward were childish.</li> <li>2. Staff behavior: for both adolescents and their mothers, staff behavior was central aspect of experience. Valued behaviors included: <ol style="list-style-type: none"> <li>a. Inclusion: feeling involved and included in one's experience (mentioned more by pediatric ICU users)</li> <li>b. Providing explanations: being given information and having things explained</li> <li>c. Interpersonal communication: adolescents wanted staff to try to get to know them and talk to them beyond their illness.</li> <li>d. Tailoring communication and interaction style: adolescents described being treated as either an adult or a child—communication more in an adult manner was preferred; they also shared they are different from both adults and from children and wanted</li> </ol> </li> </ol>
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						<p>interactions that met the needs of an adolescent.</p> <p>e.</p> <p>Respect: how staff interacted affected feeling respected—overall how care was delivered was more important than where care was received.</p>
<p>Wood et al. (2020)<sup>25</sup> United Kingdom</p>	<p>To explore perspectives regarding both the optimal environment (adult vs pediatric ICU) in which to care for critically ill adolescents No framework (inductive)</p>	<p>Qualitative/descriptive</p>	<p>HCP perspectives N = 12 (6 from adult ICUs and 6 from pediatric ICUs) 6 nurses 3 consultants 3 allied health care professionals Median time working in ICU was 12 y (3–20 y)</p>	<p>2 adult ICUs and 2 pediatric ICUs in England</p>	<p>One-on-one interviews using interview guide</p>	<p>The main finding was, What are adolescents like? which described variable views on the adolescent by health care professionals. Two additional themes included</p> <ol style="list-style-type: none"> <li>1. Needs of critically ill adolescent: medical needs and the importance of delivering appropriate care, dignity and privacy, issues of consent, and minimizing the psychological impact of the ICU</li> <li>2. Implications for staff: beliefs that parental presence was beneficial, lack of familiarity with the care of adolescents, and the emotional impact of caring for adolescents on health care professionals</li> </ol> <p>Other key findings:</p> <ul style="list-style-type: none"> <li>• Pediatric ICUs were more family centered, whereas adult ICUs were individual-centered care</li> <li>•</li> </ul>



						<p>Duration of stay and complexity of medical needs were key considerations: adolescents who require a prolonged ICU stay should be in pediatric ICU; for short stays, adult ICUs are appropriate.</p> <ul style="list-style-type: none"> <li>• should consider parental presence for procedures but should be up to the adolescent</li> <li>• Concerns that adolescent not fully considered in decision making</li> <li>• Emotional impact of caring for adolescent—death is very difficult but they also have greater chance of recovery (hopeful)</li> </ul>
<p>Zeilani and Seymour (2010)<sup>27</sup> Jordon</p>	<p>To describe the experiences of Muslim women in ICUs No framework (inductive approach)</p>	<p>Qualitative, narrative</p>	<p>Patient perspective 16 women included in the study from 2 different ICUs (ages 19–82 y) and of these, 8 were younger than 40 y</p>	<p>Adult ICU</p>	<p>One-on-one interviews Narrative analysis</p>	<p>Themes uncovered were</p> <ol style="list-style-type: none"> <li>1. Physical suffering</li> <li>2. Social suffering</li> <li>3. Spiritual suffering</li> <li>4. Suffering from the ICU technology</li> </ol> <p>*For the young adult women, social suffering was the theme most frequently described. Their children were very important to them and they thought only of their children</p>

						while in the ICU. Separation from their family made them fear death and experience loneliness. They were frustrated when ICU staff did not facilitate connection with their family. *Not specific to AYAs (older adults included)
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*Abbreviations:* IQR, interquartile range; LOS, length of stay; M, mean; PICU, pediatric ICU.

## Results

Of the 3627 records screened, 10 articles met all inclusion criteria (Fig. 2). The main reason for exclusion was lack of specificity to the AYA population.

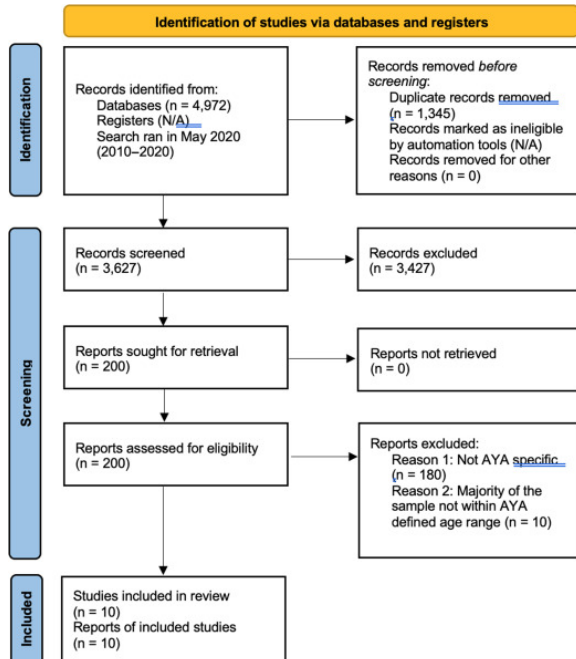


Fig. 2. PRISMA flow for search results.

## Study characteristics

### Design

Two studies<sup>19,20</sup> were descriptive/correlational in design. The remaining studies were qualitative, with 3 using focus groups<sup>12,21,22</sup> and 5 using 1-on-1 interviews<sup>23, 24, 25, 26, 27</sup> for data collection. Of these, 1 study was a qualitative evaluation of an intervention.<sup>26</sup>

### Sample

Six studies investigated family symptoms, satisfaction, or experience,<sup>19, 20, 21, 22, 23, 24</sup> with 1 of these studies including 9 mother/adolescent dyads.<sup>21</sup> The family members studied included parents, siblings, and spouses, and sample sizes ranged from 1 family unit (mother and father) to 405 family members. Three studies investigated the patient experience,<sup>21,26,27</sup> with sample sizes ranging from 7 to 16, including the adolescent perspective described in the mother/adolescent dyad study, referred to ptrbioudly.<sup>21</sup> Health care providers (nurses, physicians, allied health professionals) were interviewed in 2 studies with sample sizes of 12 to 15.<sup>12,25</sup>

Four studies focused on adolescents<sup>21,23,25,26</sup>; 2 study included younger children with adolescents<sup>22</sup>; 2 study included AYAs,<sup>12</sup> and 4 studies included samples with median/mean ages meeting inclusion criteria; however, these samples also included older adults and younger children.<sup>19,20,24,27</sup>

## Study Setting

All studies examined some aspect of the ICU experience; 4 of the 10 studies also examined acute care experiences.<sup>12,21,22,26</sup> Studies were conducted in the United States<sup>12,20,22</sup>; Sweden<sup>23</sup>; United Kingdom<sup>21,25</sup>; Czech Republic and Slovak Republic<sup>19</sup>; Denmark<sup>26</sup>; Jordan<sup>27</sup>; and Turkey.<sup>24</sup>

## Theoretic Framework

None of the studies reported a theoretical framework.

## Adolescents and Young Adults Patient Experience

Two studies specifically examined adolescent experiences in the ICU<sup>21,26</sup> and found that their experiences were impacted by interactions with their parents and health care professionals. Adolescents want to be respected as individuals, receive information and explanations directly, and be communicated with in an age-appropriate way.<sup>21</sup> Adolescents reported wanting to be involved in decision making, allowed to be in control, and respected as individuals.<sup>26</sup> They also reported that some nurses were too busy, physicians reduced them to a diagnosis, and interacting with psychologists would associate them with the stigma of mental illness.<sup>26</sup> A sense of control motivated adolescents to participate/continue treatment.<sup>26</sup> They wanted to be known beyond their medical condition by staff<sup>21</sup>; get a break from their illness, treatments, and overprotective parents; and continue to be connected with their social networks and peers.<sup>26</sup> In Villadsen and colleagues'<sup>26</sup> study, adolescents who participated in a social education intervention tailored to the needs of the adolescent population with acute or chronic critical illness felt empowered to set their own goals, developed independence within the inpatient setting, and felt connected to peers. The adolescent participants developed a strong relationship with the social educator who delivered the intervention. Adolescents in the study by Wood and colleagues<sup>21</sup> reported that both the ICU environment and health care professionals' behaviors positively or negatively affected their experience. Adolescents felt surrounded by old people in adult ICUs, whereas in pediatric ICUs adolescents shared that activities were childish. How they were treated by health care professionals was more important to adolescents than the care setting.<sup>21</sup> Adolescents thought the behaviors of health care professional were positive if they made the adolescent feel included, provided information and explanations, connected them on a personal level, and tailored communication to the adolescent's needs. When these positive behaviors occurred, the adolescent felt respected. Adolescents reported being treated as either an adult or a child; while they preferred to have a more adult approach to communication, adolescents emphasized that they are different from both adults and children.<sup>21</sup>

One study described the experiences of women in the ICU.<sup>27</sup> A theme specific to the young adult (20–39 years) women in this sample was their focus on their young children. These young adults experienced extreme distress and suffering due to being separated from their children during their stay in the ICU. A participant described their important connection to their children: "I feel my children are the closest to my heart...."<sup>27(p.170)</sup> Their sense of purpose stemmed from their role as mother and separation from their family was intertwined with their fear of death. Mothers in this study never stopped thinking of their children, and many requested that nurses facilitate contact with their families. Nurses did not consistently respond to these requests, however, possibly not fully understanding the patients' deep need to be close to their children.

## Family experience of adolescents and young adults in ICUs

Six studies described parent or family member experiences in the ICU.<sup>19, 20, 21, 22, 23, 24</sup> There was no difference in anxiety or depression symptoms for family members related to where care was received—adult ICU versus pediatric ICU.<sup>19</sup> Age of the patient, however, was found inversely associated with symptoms of depression among family members (as age decreased, symptoms of depression increased).<sup>19</sup> In a case study in which the parents of a 19-year-old woman were interviewed about their ICU experiences, themes included a strong need to be with their daughter; uncertainty regarding her prognosis, survival, and quality of life; feeling

the health care team abandoned them by not allowing them to be with their daughter; guilt that they may not be fulfilling moral obligations to her; and fluctuations in their family routines and responsibilities.<sup>23</sup>

Although parents recognized the high level of support and attention that their child received in the ICU setting,<sup>22</sup> they felt the environment posed challenges to their efforts to be at their child's bedside. Challenges included visitation rules that did not accommodate younger siblings; the ICU team's limited understanding of the needs of the entire family; lack of chairs in their child's room; extended waiting periods outside the patient room without updates and not knowing when they could return to the bedside; and lack of accommodations for family members spending prolonged periods in the hospital.<sup>22</sup> Although family members highly valued the information that health care professionals imparted about their child,<sup>21</sup> this communication was often perceived to be insufficient.<sup>22</sup> note, family members of patients in pediatric ICUs had better comprehension of the patient's diagnosis than those cared for in adult ICUs,<sup>19</sup> suggesting differences in family engagement. In the dyadic study of adolescent/mother perspectives about pediatric versus adult ICU settings, mothers, like adolescents, emphasized the importance of how providers approached interactions with their adolescent and the needs to receive information and explanations and to include parents as partners in care.<sup>21</sup> Mothers of adolescents surmised that a barrier to proactive palliative care was health care professionals' reluctance to broach the topic of death with a young person.<sup>22</sup>

### Health care professionals' experience of caring for adolescents and young adults

Two studies reported the experiences of health care professionals caring for adolescents in ICUs.<sup>12,25</sup> Comfort in caring for adolescents and supporting their families differed among health care professionals (nurses, consultants, and allied professionals) based on their experiences caring for adolescents and knowledge about this age group.<sup>25</sup> These health care professionals considered the pediatric ICU better equipped to care for adolescents and their families. They reported that the decision to admit to pediatric or adult ICU should be determined by complexity of patient needs but also consider individual factors. They thought short, 1-time admissions for adolescents could be appropriate for an adult ICU, whereas chronic conditions and ongoing specialized needs were appropriate for a pediatric ICU.<sup>25</sup>

Health care professionals felt that caring for adolescents may have more emotional impact than caring for younger children due in part to adolescents' ability to voice concerns.<sup>25</sup> Involvement of adolescents in care decisions and providing explanations were considered important.<sup>12,25</sup> In a study of physician experiences about advance care planning with adolescents undergoing hematopoietic stem cell transplant, physicians expressed concerns about adolescents' developmental capacity to make informed decisions and also noted differences in decision-making processes among adolescent patients and their family members.<sup>12</sup> In both studies, health care professionals described the emotional impact of the death of an adolescent in the ICU,<sup>12,25</sup> especially when health care professionals are not used to caring for such young patients.<sup>25</sup> In the study focused on physicians caring for patients who underwent HSCT and were admitted to the ICU, physicians expressed that they need to be certain that the patient will not survive before they felt comfortable bringing up the possibility of death with an adolescent and their parents.<sup>12</sup>

## Discussion

The scoping review identified paucity of studies focused on AYA experiences in the ICU setting. The authors selected the NCI AYA definition in this review to be as broad as possible to ensure they gathered literature on both adolescent and young adult experiences. Although AYA is recognized as a distinct area of research, most studies in this scoping review focused on either adolescents or young adults. Ten studies met inclusion criteria; however, 4 of these studies<sup>19,20,22,24</sup> did not provide any data or analysis specific to adolescents or young adults.

A question raised in 1 of the reviewed studies was whether adolescents should be cared for in an adult ICU or a pediatric ICU.<sup>21</sup> In this study, adolescents reported that they cared less about the type of ICU and more about how health care professionals interacted with them and involved them as experts in their own care.<sup>21</sup> Beyond adolescent preferences, there is a question of whether quality of care differs for adolescents in pediatric ICUs or adult ICUs. In a large study that explored the ICU care of adolescents in the United Kingdom, adolescent mortality did not differ based on whether care was delivered in an adult ICU or a pediatric ICU.<sup>10</sup> Findings suggest, however, that care of adolescents in both pediatric ICU and adult ICU settings may not meet their unique needs, because they may be triaged to an adult or pediatric ICU based on their diagnoses and need for medical or surgical intervention, rather than the psychosocial factors that may influence their quality of care.<sup>10</sup> The question of which ICU setting is best for adolescents remains unanswered. Adolescents are a small percentage of the ICU population in both care environments,<sup>10</sup> posing a challenge for research. Large samples of adolescents are needed to fully examine psychosocial variables that may influence quality of care.

AYAs with complex chronic conditions have frequent interactions with the health care system and may have numerous stays in an ICU. Only 1 study in this review, however, included a sample of adolescents with chronic critical illness.<sup>26</sup> Adolescents with chronic conditions may have to transition from a pediatric to adult setting as they age out of pediatrics. Adolescents and their parents often feel these transitions are abrupt and perceive a lack of partnership with the health care team during this process.<sup>28</sup> These transitions in care represent an important opportunity for further research to elicit the needs and preferences of adolescents with chronic conditions and their families as they navigate transitions from child-focused to adult-focused care environments.

None of the reviewed studies focused solely on experiences of young adults in the ICU; however, the authors were able to cull specific data about young adult women from 1 study. An important finding from this study specific to young adult female patients was the importance of remaining connected to their children.<sup>27</sup> This point is illustrated in the case presented to frame the scoping review. In retrospect, the team recognized missed opportunities to facilitate Violet's connection to her children, which could have better supported her psychosocial well-being. Incorporating child life specialists who are experts in developmentally appropriate coping and psychological preparation into ICU teams could address both the needs of the young adult patient and those of any young children in their family.<sup>29</sup> Child life specialists have the expertise to facilitate developmentally appropriate visits with AYA patients and their children and also support the ICU team, particularly in adult ICUs, where ICU staff may be unaccustomed to involving young children in ICU visitation. Although child life specialists often are called in to assist in end-of-life situations, developing an interprofessional AYA team led by a child life specialist may be a way to address the unique needs of AYAs in the ICU setting.

This scoping review highlights that care often is not tailored to the unique needs and experiences of AYA patients.<sup>21,26</sup> This was emphasized in adolescents' expressed need to have health care professionals tailor their communication and interaction style to their age.<sup>21</sup> In this review, the authors found that a social-pedagogical intervention that allowed adolescents to talk and clinicians to hear about the patient's personal experiences was considered helpful and motivating.<sup>26</sup> The authors recommend continued study of this intervention to determine if it will meet the needs of AYAs in the ICU setting.

No guidelines exist for the care of AYAs in ICUs, which is likely due to the lack of a robust evidentiary base to inform recommendations. This scoping review is a critical first step toward the development of a practice-based framework to guide ICU care for AYAs. The reviewed studies suggest that adolescents recognize their own unique needs. To ensure AYA patients and their families can fully engage as partners in care, health care professionals must address these unique needs to optimize the ICU experiences and outcomes of AYAs. Interventions cannot be developed without understanding the AYA perspective about critical care.

None of the reviewed studies describes a theoretic framework. This may be due to the inductive approach to gathering data taken by most of these studies, but it also may speak to the need for AYA-specific frameworks to guide ICU research and practice. To address the variability in ICU care for adolescents across care settings and across countries, European Society of Pediatric and Neonatal Intensive Care (ESPNIC) developed a mnemonic (the 6 Ps) to use when ICU professionals care for adolescents: privacy, permission, DVT prophylaxis, personal life, puberty, and practice issues.<sup>30</sup> Implementation of the 6 Ps and development of additional clinical tools are important steps toward better meeting the needs of AYAs in the ICU.

An emerging body of literature calls for the early integration of palliative care into the cancer journey of AYAs.<sup>14,15,31,32</sup> The authors argue that early and integrated palliative care is a critical direction for improving the care of AYAs with chronic critical illness, because exacerbations and complications of pediatric-onset chronic illnesses are reasons for ICU admissions among AYAs.<sup>6</sup> In a study about advance care planning for children, adolescents, and young adults with complex chronic conditions, bereaved parents valued early advance care planning, and it was associated with better quality of life.<sup>33</sup> There is a paucity of literature exploring the experiences of AYAs and their family members with palliative care in the ICU, including primary and specialty palliative care, serious illness communication, advance care planning, and transitions to end-of-life care. Although advance care planning before critical illness is optimal, in 1 of the studies included in this review, providers of adolescents undergoing HSCT expressed that adolescents and their families may not know what their preferences are until they experience critical illness.<sup>12</sup> In a study conducted in 2010, findings revealed that adolescents with leukemia or lymphoma were more likely to die in the ICU than other settings, yet end-of-life discussions were more likely to occur during the last 7 days of life.<sup>18</sup> Insufficient and/or delayed ICU palliative care integration continues and barriers to early and proactive palliative care consultation still are being overcome.<sup>34,35</sup> In 1 study the authors reviewed, parents perceived provider reluctance to discuss the possible death of their child.<sup>22</sup> Health care teams are tasked with balancing the developmental readiness of the adolescent for end-of-life discussions,<sup>12</sup> the parents' desire to protect their child from difficult conversations but also involve them in decisions about their care,<sup>22</sup> and health care professionals' discomfort with the potential death of a young person.<sup>12,25</sup> Balancing the perspectives of these three stakeholders presents unique challenges to engaging in serious illness conversations, advance care planning, and end-of-life decisions with AYAs. Specialty palliative care consultation teams have the expertise to support health care professionals, patients, and their families through the difficult emotional process of serious illness communication in the ICU.<sup>34, 35, 36</sup> Interprofessional palliative care teams can build the capacity of ICU teams through collaborative opportunities to learn about serious illness conversations and advance care planning for AYAs.

There were missed opportunities for primary and specialty palliative care in Violet's case, a young adult with chronic critical illness. Did this occur because the health care team had different expectations for her prognosis than they would have had for an older adult? Would advance care planning early in her illness trajectory have laid the groundwork for more palliative care involvement? Did the team fully consider this young adult's developmental stage in life and how it may influence how and who should be involved in end-of-life discussions? Research regarding the specialized palliative care needs of specific ICU populations is in its nascency and it is critical that the unique palliative care needs of AYAs are explored. Dyadic approaches to research that involve the AYA and their family member as participants in which their perspectives are elicited together and compared, such as that of Wood and colleagues,<sup>21</sup> could be promising given the close family relationships that may exist for AYAs. Greater insight into the experiences of AYAs in the ICU will allow palliative care to be tailored to the needs of adolescents, young adults, and their families.

This scoping review indicates critical directions for future ICU AYA research. Given the small percentage of AYAs in both adult ICU and pediatric ICU settings, future studies need to be multisite with specific samples of AYA ICU patients and their families. The authors propose the following research questions:

1. Do critically ill AYA patients have a more severe psychological symptom burden compared with older critically ill patients?
2. Are AYA family members more likely to support life-sustaining interventions, such as mechanical ventilation, dialysis, vasopressor support, and cardiopulmonary resuscitation for critically ill AYA patients, compared with older critically ill adults?
3. What is the frequency of identifying a surrogate decision maker (SDM) among critically ill AYA patients compared with older critically ill adults? Who are the SDMs for critically ill AYAs?
4. What are the unique communication/interpersonal dynamics of critically ill AYA patients and their families and health care providers, compared with non-AYA patients?
5. What are the perspectives of health care professionals in pediatric ICUs and adult ICUs regarding caring for the chronically critically ill AYA population?
6. Could a Delphi approach with AYA patients, families, and health care professionals be used to further understand the unique needs of this distinct ICU population and begin to lay the foundation for the development of practice guidelines for AYA ICU care?
7. In what ways do the perspectives of AYA patients and their family members about advance care planning change in the context of critical illness?

## Limitations of this review

This review was limited to case studies and primary research in the English language; therefore, findings may not represent all languages/cultures. Only 10 studies met inclusion criteria due to a paucity of literature in this area and/or limitations of the search strategy. Although AYAs may be included in adult ICU or pediatric ICU research, samples of ICU patients tend to be heterogeneous with only a small percentage of AYA patients; thus, it is difficult to distinguish differences among the experiences of children, adolescents, young adults, and adults. Because professional bodies define the age range of AYA differently, researchers may focus on differing age ranges when studying adolescents, young adults, or AYAs, which makes comparison of findings in the AYA literature more challenging. The authors applied the NCI definition of the AYA age range for article inclusion; thus, the scoping review findings might be different if another definition of AYA had been applied.

## Summary

In conclusion, this scoping review underscores the limited literature specific to adolescents, particularly to young adults in the ICU setting. The authors' analysis of the perspectives of patients, family members, and health care professionals indicates that the unique developmental needs of adolescents, and likely young adults, may not be adequately met. Further insights are needed to seize opportunities to tailor ICU care to the developmental stage of the AYA population and improve family-centered care. Without further exploratory research, the unique needs of AYAs and their families will remain poorly understood. Additionally, the scoping review suggests that strengthening ICU professionals' serious illness communication skills may improve the experience of AYAs and their families in the ICU and may decrease the distress of the health care professionals caring for this population.

## Clinics care points

- From the adolescent and parent perspective, it may be less important where an adolescent is cared for (pediatric ICU vs adult ICU) and may be more important that an adolescent is treated as a unique individual.
- AYA patients and their family members need to be fully engaged in care, and the health care team needs to provide family-centered support.
- ICU teams need access to AYA experts, such as child life specialists and palliative care specialists, to inform and guide their serious illness conversations with AYAs and their family members.
- Evidence is needed to develop practice guidelines for AYA care in both adult ICU and pediatric ICU settings.



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