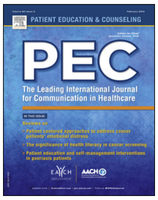
Patient Education and Counseling xxx (2017) xxx–xxx

Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pateducou



Review article

Patient-centered communication between adolescent and young adult cancer survivors and their healthcare providers: Identifying research gaps with a scoping review

Jessica R. Gorman[a,*], Daniel Standridge[b], Karen S. Lyons[c], Diane L. Elliot[d], Kerri Winters-Stone[c], Anne K. Julian[a], Jennifer Weprin[c], Martin Storksdieck[e], Brandon Hayes-Lattin[f]

[a] *School of Social and Behavioral Health Sciences, Oregon State University, Corvallis, USA*
[b] *School of Biological and Population Health Sciences, Oregon State University, Corvallis, OR, USA*
[c] *School of Nursing, Oregon Health & Science University, Portland, USA*
[d] *Department of Medicine, Oregon Health & Science University, Portland, USA*
[e] *School of Public Policy, Oregon State University, Corvallis, USA*
[f] *Knight Cancer Institute, Oregon Health & Science University, Portland, USA*

ARTICLE INFO

Article history:
Received 22 May 2017
Received in revised form 23 August 2017
Accepted 30 August 2017

Keywords:
Communication
Patient-centered
Intervention
Review
Adolescent and young adult
Cancer

ABSTRACT

Objective: To conduct a scoping literature review to identify practices or programs that promote AYA patient-centered communication.
Methods: Between January and May of 2016, we applied standard scoping review methodology to systematically review articles. We considered peer-reviewed, English language articles written at any phase of intervention research. Both qualitative and quantitative studies were eligible, and no additional search restrictions were applied. We retained articles that included explicit or implicit outcomes for one of the six functions of patient-centered communication in cancer care. At least two independent reviewers assessed the articles.
Results: We screened a total of 4072 titles and abstracts, retaining 27 for full-text review. Ultimately, eight titles met the review's inclusion criteria. We categorized each publication by the action or setting used to improve patient-centered communication, resulting in five categories. Most studies were not included because they did not include a patient-centered communication outcome.
Conclusion: This area of research is still emerging, as indicated by the small number of eligible studies and predominance of qualitative, descriptive, pilot, and feasibility studies with small sample sizes.
Practice implications: Our results suggest a clear need to develop and evaluate interventions focused on improving patient-centered communication between AYA survivors and their healthcare providers.

Contents

---

* Corresponding author at: Oregon State University, Oregon State University, 2250 SW Jefferson Way, Waldo Hall 410, Corvallis, OR 97331 USA.
E-mail addresses: Gorman@oregonstate.edu (J.R. Gorman), standrid@oregonstate.edu (D. Standridge), lyonsk@ohsu.edu (K.S. Lyons), elliotd@ohsu.edu (D.L. Elliot), wintersk@ohsu.edu (K. Winters-Stone), juliana@oregonstate.edu (A.K. Julian), weprinj@ohsu.edu (J. Weprin), storksdieck@oregonstate.edu (M. Storksdieck), hayeslat@ohsu.edu (B. Hayes-Lattin).

http://dx.doi.org/10.1016/j.pec.2017.08.020
0738-3991/

Please cite this article in press as: J.R. Gorman, et al., Patient-centered communication between adolescent and young adult cancer survivors and their healthcare providers: Identifying research gaps with a scoping review, Patient Educ Couns (2017), http://dx.doi.org/10.1016/j.pec.2017.08.020

1. Introduction

Adolescents and young adults (AYA) diagnosed with cancer must navigate a complicated healthcare system that often does not meet their unique medical and psychosocial needs [1–7]. Cancer and cancer treatment interrupt AYA survivors' physical, social and psychological development, affecting many areas of life including education, career and family planning as well as physical, emotional and financial wellbeing [5,8]. Uncertainty about long-term and late effects is also common among AYA cancer survivors and negatively affects quality of life [9,10]. Many priority concerns for AYA cancer survivors, such as fertility and sexual health, require special consideration and are often inadequately addressed [11–14]. Effective communication between AYA survivors and their healthcare providers could be an integral strategy to help survivors cope with the impact and uncertainty of cancer [10] and to enhance long-term quality of life by addressing their concerns [15,16]. However, we know little about which interventions might be most effective at optimizing patient-provider communication specific to AYA survivors.

Historically, AYA cancer survivors have been underrepresented in cancer studies and overlooked for programs that may be helpful during and after treatment [17]. Programs and models of care have begun to emerge that meet the needs of the AYA population as a whole. Patient-centered communication is a framework that can be applied and tailored to meet the diverse and fluctuating needs that arise during AYA cancer survivorship, defined as the time of diagnosis onward. This framework is consistent with the Institute of Medicine recommendations, and is critical to the successful delivery of comprehensive healthcare services [18–20]. Epstein and Street define the approach to include actively eliciting patients' perspectives, understanding the influence of social and cultural context on patients' needs, and arriving at a decision that is aligned with patients' values [18]. Effective communication during opportune patient-provider interactions has the potential to improve mental and physical health outcomes [18,20]. However, AYA survivors are a diverse population, varying in cancer type and treatment, demographics, and developmental stages and ages (from 15 to 39 years) [21,22]. This diversity makes a uniform approach to the care of and communication with AYA survivors untenable, and necessitates the development of targeted, patient-centered survivorship programs. It is possible that there are strategies underway to improve patient-centered communication for AYA cancer survivors, but these have not been systematically gathered and reviewed for efficacy or best practices to direct future research and translation to clinical practice.

With this in mind, we conducted a scoping review of the literature to identify interventions that are available to promote patient-centered communication between AYA cancer survivors and their healthcare providers across the continuum of cancer survivorship, from the time of their diagnosis onward. Specifically focusing on interventions to improve patient-centered communication outcomes is required to advance our knowledge of whether and how different aspects of communication can be improved to effectively address AYA survivors' diverse concerns. This study was limited to research with measured outcomes focused on one of the six functions of patient-centered communication in cancer care. These include: 1) strong patient-family/clinician relationships (e.g., trust, involvement of family, patient feels understood); 2) effective information exchange (e.g., patient asks questions); 3) validation of emotions (e.g., healthcare provider expresses empathy); 4) acknowledgement, understanding and tolerance of uncertainty; 5) patient participation in decision making; and 6) enabling patient self-management/coordination of care [18]. The goals of this scoping review are to summarize existing research with patient-centered communication outcomes and to guide research and clinical efforts toward improving communication on the issues that are particularly salient to AYA cancer survivors.

The primary research question guiding the scoping review was:

RQ1: What practices or programs are available to improve patient-centered communication for AYA cancer survivors?

Secondary research questions were:

RQ2: What communication approaches are used?

RQ3: What functions of patient-centered communication are evaluated?

RQ4: What is the evidence for effectiveness/efficacy of these approaches?

2. Methods

Scoping review is a methodology that provides a preliminary assessment of the size and scope of the research literature, and identifies the nature and extent of evidence. We following the scoping review methodology proposed by Arksey and O'Malley [23] and elaborated on by others [24,25]. Scoping review is a systematic approach to a wide review of the literature that includes the following steps: 1) identify research questions and domains to explore; 2) identify relevant research via databases and other sources; 3) select studies relevant to the research questions; 4) chart the relevant data from the selected studies; and 5) collate and summarize the results [23]. Arksey and O'Malley exclude assessment of the quality of studies from their methodology, but others argue that a complete synthesis of knowledge, including concepts, evidence, and gaps in research, necessitates an assessment of the quality of evidence [24]. We summarize quality of evidence, but this is unique from a systematic review because

Please cite this article in press as: J.R. Gorman, et al., Patient-centered communication between adolescent and young adult cancer survivors and their healthcare providers: Identifying research gaps with a scoping review, Patient Educ Couns (2017), http://dx.doi.org/10.1016/j.pec.2017.08.020