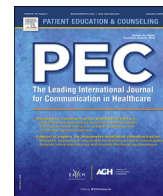




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## Patient Education and Counseling

journal homepage: [www.elsevier.com/locate/pateducou](http://www.elsevier.com/locate/pateducou)



# Adolescent cancer patients' perceived quality of cancer care: The roles of patient engagement and supporting independence

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### ARTICLE INFO

#### Article history:

Received 13 November 2017

Received in revised form 2 April 2018

Accepted 8 April 2018

#### Keywords:

Quality of care

Patient engagement

Adolescent cancer

Patient-provider relationship

### ABSTRACT

**Objectives:** A lack of focus on variation in engagement among cancer populations of differing developmental stages led us to examine the associations between patient engagement, the patient-provider relationship, cognitive development, readiness to transition to adulthood (transitional readiness) and perceived quality of care.

**Methods:** A sample of 101 adolescent cancer patients (diagnosed 10–20 years) completed survey items concerning patient engagement, dimensions of the patient-provider relationship, cognitive development, transitional readiness, and demographic characteristics using an iPad/tablet during a routine clinic visit.

**Results:** Patient engagement was not significantly associated with perceived quality of care ( $b = .02$ , 95% CI:  $-0.06, 0.11$ ). Instead, adolescents with providers that supported their independence ( $b = .34$ , 95% CI:  $0.17, 0.52$ ) were significantly more likely to perceive higher quality care.

**Conclusion:** Supportive patient-provider relationships are an integral part of adolescents' perceptions of quality of care. Adolescents are still gaining important skills for navigating the medical system, and the patient-provider relationship may provide an important scaffolding relationship to help adolescents build independence in their treatment experience.

**Practice implications:** Identifying potential mechanisms through which adolescents can provide their opinion, ask questions, and participate in their treatment plan will help in supporting adolescent independence and improve quality of care.

Published by Elsevier B.V.

## 1. Introduction

Adolescents with cancer report feeling out of place and without a home in an oncology setting that is usually geared towards younger children or older adults [1,2]. While the American Society of Clinical Oncology [3] has highlighted the need for improvement in quality of care, little attention has been paid to how perceptions of quality of care may vary in patients of different developmental stages. The Institute of Medicine [4] developed a framework for improving the quality of cancer care in the United States that is centered around patient engagement as the primary driving force.

Engaged patients are able and willing to manage their own healthcare [5], are more likely to receive recommended screening tests, have lower medical costs, engage in health enhancing self-management behaviors, and report higher quality care [6–8]. Our paper will focus on exploring quality of care in the adolescent developmental stage (defined as ages 10–20 years) because it represents a stage of life where individuals change more than any other, outside of infancy, and these changes directly impact an individual's ability to engage in their healthcare [9].

Changes in brain structure occur gradually across adolescence and into young adulthood. Information processing speed, the capacity to plan ahead, and the ability to consider multiple sources of information in decision-making develop throughout adolescence [9–14]. Cognitive function develops simultaneously with changes in the parent-child relationship [15–18], increases and then decreases in risk-taking and sensation-seeking behaviors [9,19], and improvements in emotion regulation

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[20]. One of the primary ways through which patients engage in their healthcare is through the medical decision-making process, a complex and emotionally-taxing experience. The numerous developmental changes adolescents are experiencing may make it difficult for them to participate in some aspects of medical decision-making, like the decision to pursue a specific course of treatment, without the help of a parent or healthcare provider.

The Institute of Medicine's [4] framework emphasizes the patient-provider relationship as the primary mechanism through which we can increase patient engagement and ultimately improve quality of care. The current literature is limited on a clear understanding of the important dimensions of the patient-provider relationship in adolescent oncology, and if this relationship functions the same as it does in adult cancer populations [21]. The limited research suggests adolescents want to play a role in treatment decision-making, receive developmentally appropriate information, and feel like their values are being respected [2,22–24]. These preferences represent aspects of patient engagement, but it is unclear how the patient-provider relationship may be able to support these preferences considering the cognitive and emotion regulation skills adolescents are continuing to develop.

The purpose of this study was to examine the association between patient engagement and perceived quality of care in adolescent cancer patients. We defined adolescent cancer patients as individuals in their second decade of life and diagnosed between the ages of 10–20 to capture patients in the middle of adolescence as well as those transitioning in and out of this developmental stage [9]. We hypothesized that adolescents with more engagement will perceive higher levels of quality of care. The patient-provider relationship has been conceptualized as the primary mechanism through which patient engagement can be increased, and there is a lack of a clear understanding of how this relationship is structured in adolescent cancer care [21]. Therefore, a secondary aim of this study was to explore the relationship between different dimensions of the patient-provider relationship and perceived quality of care in adolescent cancer patients.

## 2. Methods

### 2.1. Participants

Participants were eligible for study inclusion if they had a recent cancer diagnosis (either initial diagnosis or recurrence) at least 3 months previously at the age of 10–20 years, were treated with chemotherapy and/or radiation, had a reading and writing knowledge of English, and were either receiving therapy or less than 2 years from the end of therapy. The age range of 10–20 years of age at diagnosis was chosen to account for developmental changes that occur across this time, the legal implications of minor patients, and cross-cultural variations in the definition of adolescent patients [25]. Patients were excluded if they had a neurodevelopmental disorder or a physical disability that would prevent them from completing the survey (e.g. blindness).

Eligibility for the study was determined via chart review by a member of the research team or clinical staff at the two recruitment sites. A total of 118 participants fit the inclusion criteria, and 111 were approached concerning the study. Of the 111 approached, 104 individuals agreed to participate and 103 completed the survey (Fig. 1). The final participation rate for the survey was 92.3%.

### 2.2. Recruitment and data collection

Institutional Review Board (IRB) approval was received by Connecticut Children's Medical Center, and honored by the Yale Medical School IRB and the University of Connecticut IRB. A member of the clinical staff or research team screened the daily appointments for eligible participants, and approached eligible participants during their routine clinic visit. If participants expressed interest in the study, the principal investigator or other member of the research team conducted the consent and assent process and administered the survey using an iPad/tablet.

The anonymous survey was developed using Qualtrics; IP addresses were not collected and email addresses were not linked to individual survey responses. Parental consent and participant assent (when applicable) was documented within the survey, and

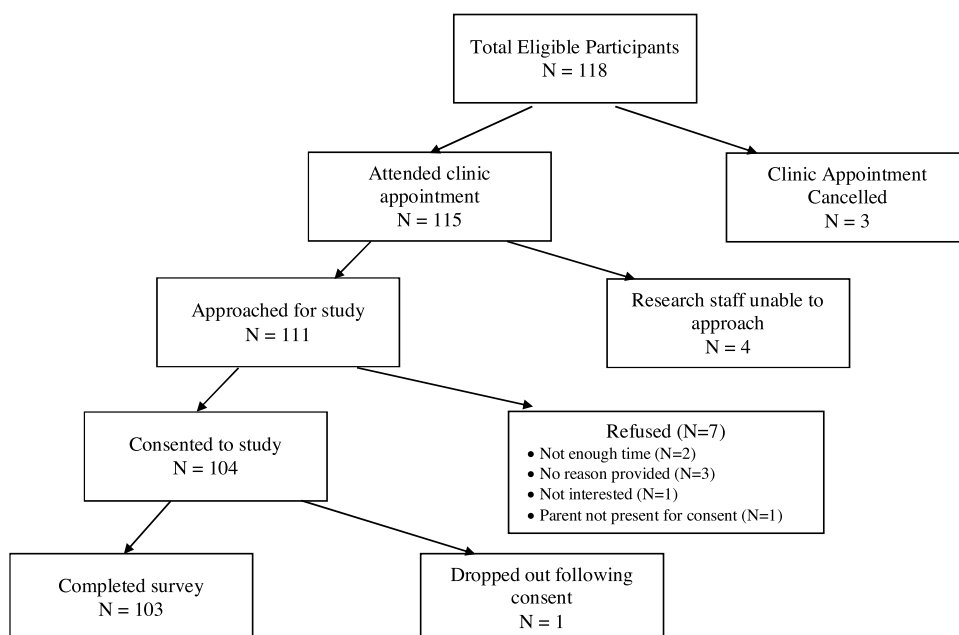


Fig. 1. Flow chart of the study recruitment process, and reasons for not enrolling in the study.

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