

A patient-centered approach to the re-development of supportive care services for oncology adolescent and young adult (AYA) patients across the Rossy Cancer Network

Gligorka Raskovic, MHA; Rebecca Fox, BA; Warren Sateren, Epidemiologist; Doneal Thomas, M.Phil, M.Sc; Ivan Barrera, MD; Gerald Batist, MD; Michael Palumbo, MD; Thierry Muanza, MD; Nathalie Johnson, MD; Aline Mamo, PhD; Thierry Alcindor, MD; Robert Turcotte, MD; Ari Meguerditchian, MD; Petr Kavan, MD, PhD

BACKGROUND

Most AYA pts in the Rossy Cancer Network (RCN) are seen in adult oncology settings tailored to the medical and supportive care needs of the general cancer population.

Even though a variety of clinical and supportive care services is currently available to this patient population, several service gaps remain.

OBJECTIVES

The main goal of this study is to conceptually redevelop the current oncology AYA model of care in order to **enhance QOL outcomes for patients at three McGill affiliated hospitals** (McGill University Health Centre, Jewish General Hospital and St. Mary's Hospital Center):

Key project objectives are:

- Understand patient satisfaction with the current level of care
- Identify concrete strategies to improve QOL outcomes for this patient population

METHODOLOGY

AMBULATORY ONCOLOGY PATIENT SATISFACTION SURVEY (AOPSS)

AOPSS scores of AYA patients* (age 18-44, n=127), seen across the RCN from 2012 to 2016, were compared to AOPSS scores of patients age 45+ (n=2,163). The **Pearson Chi-Square** test was used to examine differences between the two data sets. A separate analysis was carried out to examine further the differences between two subsets of the AYA patient sample (i.e. patients 18-34 years of age and patients 35-44 years of age).

DELPHI STUDY

A literature review identified 24 sample strategies (Zebrack et al, 2010) that could be incorporated in the current model of care to address AYA QOL service gaps. A **Delphi panel** consisting of oncology health care professionals (HCPs) and AYA cancer patients rated the importance of each sample strategy on a 7-point Likert scale. **ANOVA** was performed to examine the differences between the two data sets. P- value ≥ 0.05 was used as a cutoff for significance.

TABLE 1
Participant Demographics: Healthcare Professionals Panel

Profession	Number of participants	
	Round 1 (n=31)	Round 2 (n=27)
Oncologist	6	6
Surgeon	5	3
Radiation Oncologist	2	1
General Practitioner	1	1
Medical Resident	1	1
Psychiatrist	2	1
Psychologist	3	3
Physiotherapist	1	1
Occupational Therapist	1	1
Social Worker	1	2
IPO Nurse	5	4
Dietician	1	1
Oncology Pharmacist	1	1
Patient Educator	1	1

TABLE 2
Participant Demographics: Patient Panel

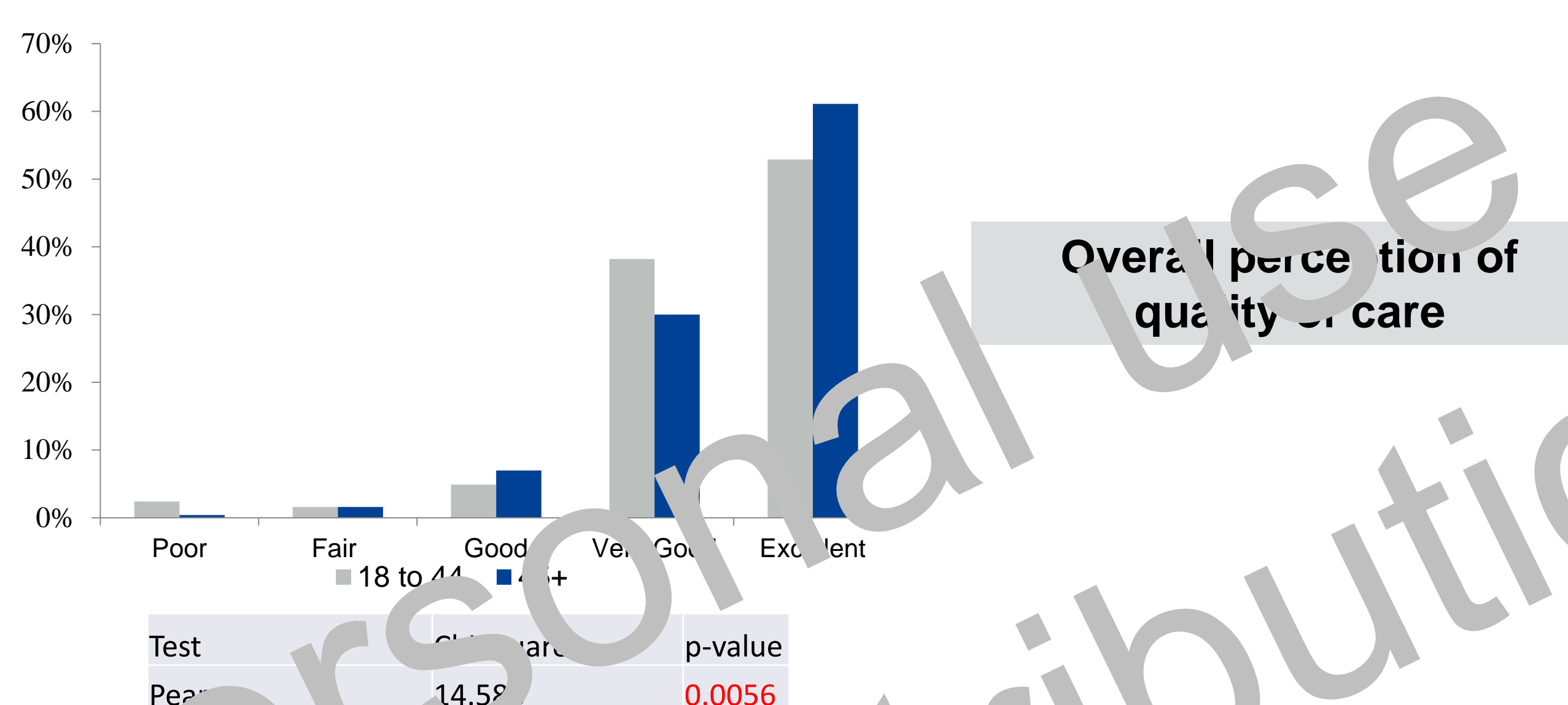
Cancer Diagnosis	Number of participants	
	Round 1 (n=31)	Round 2 (n=21)
Breast	17	12
Lymphoma	2	2
Gastro-intestinal	5	3
Testicular	3	1
Sarcoma	3	2
Brain	1	1

Note: The McGill AYA Oncology Program's upper age limit is higher compared to the AYA age limit proposed by the National Cancer Institute Progress Report Group (ages 18-39) and the age bracket proposed by the Canadian Task Force on Adolescents and Young Adults with Cancer (ages 15-29 (39))

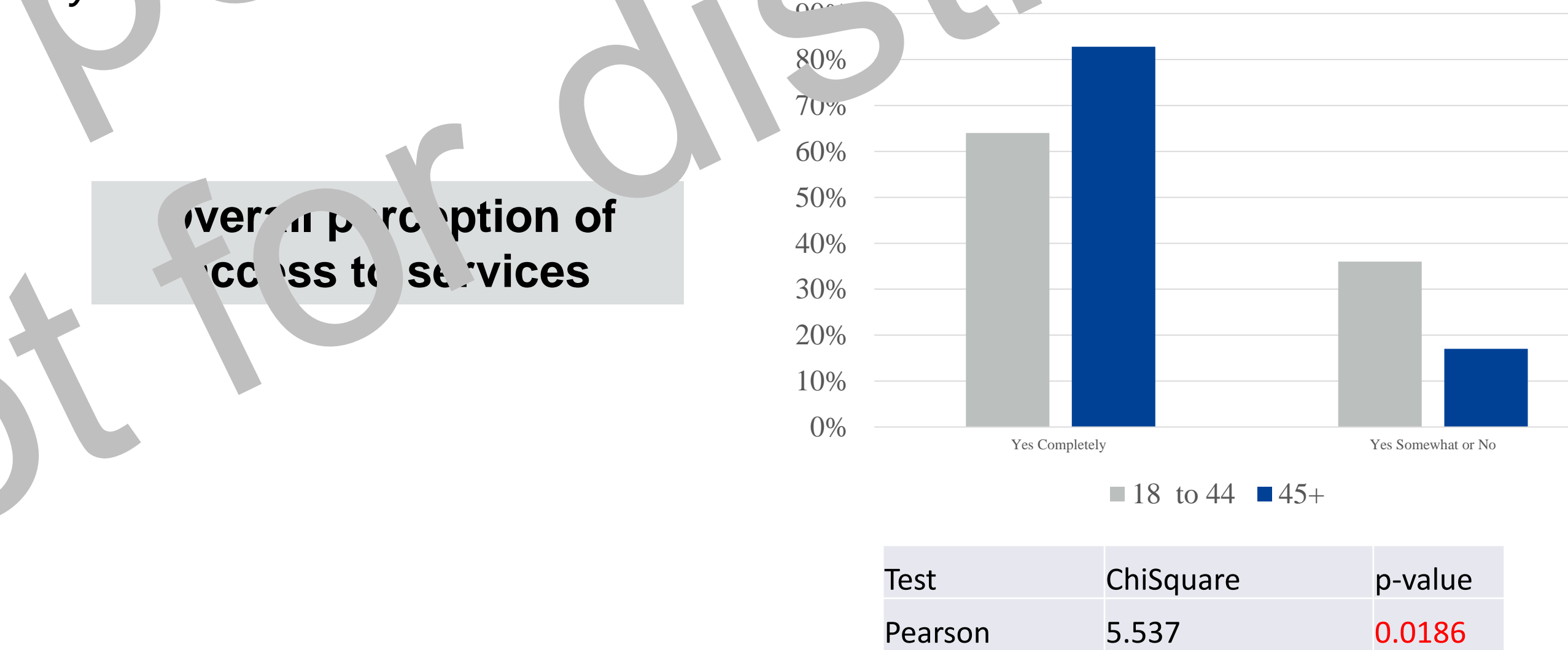
AMBULATORY ONCOLOGY PATIENT SATISFACTION SURVEY RESULTS

Do younger cancer patients have different impressions of patient experience and satisfaction compared to older cancer patients?

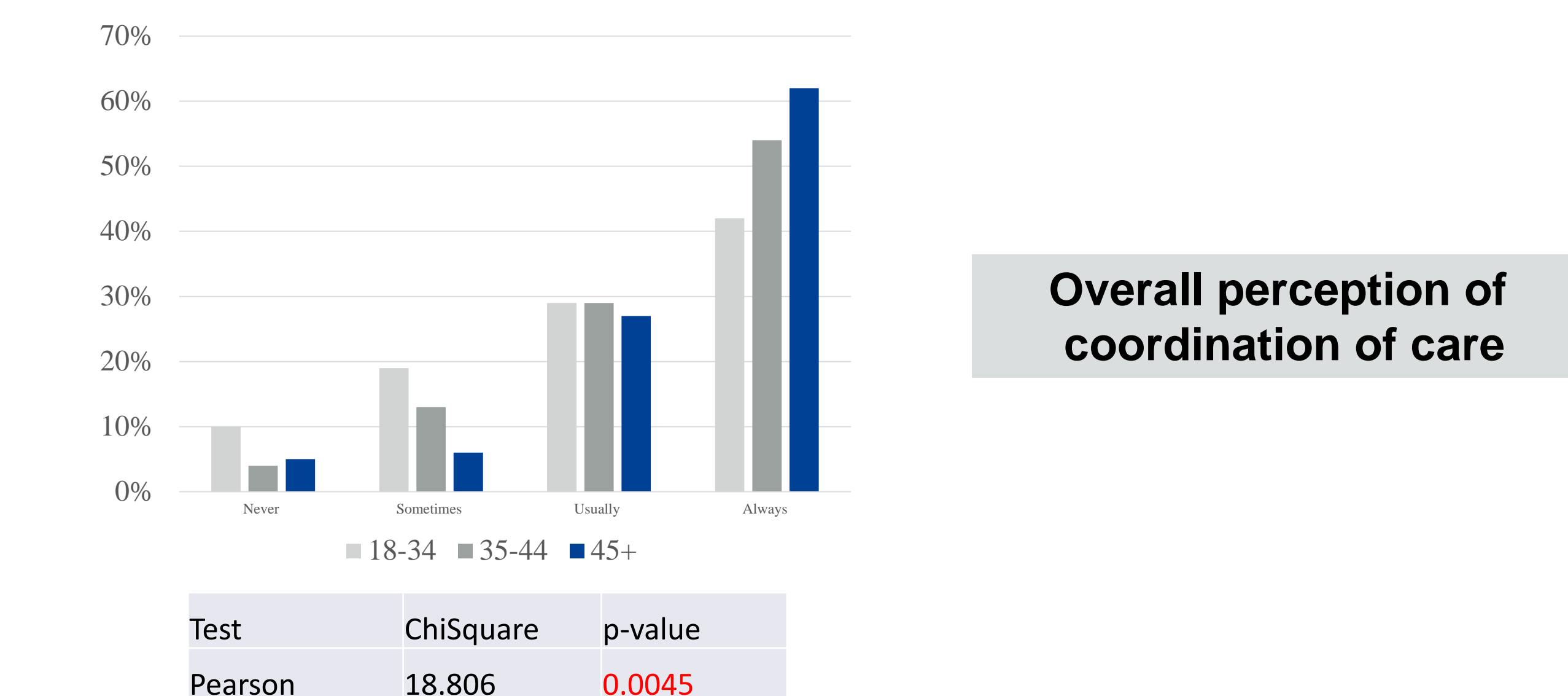
Q79: "Overall, how would you rate the quality of your care in the RCN hospitals in the past 6 months?"



Q80: "In the past 6 months, did you receive all of the services you thought you needed for your cancer treatment?"



Q85: "If you received cancer treatment in the RCN hospitals and somewhere else, do you feel that your overall care was well coordinated?"



DELPHI STUDY RESULTS

TABLE 3:
Top Ten Ranking Sample Strategies for Improving QOL and Quality of Care Throughout the Cancer Care Continuum

Strategy	Combined Score (Patient Panel + HCP Panel) (n=48)		HCP Panel (n=27)	Patient Panel (n=21)	p-value
	Mean Importance Score	Rank	Mean Importance Score	Mean Importance Score	
Offer patient education programs that provide AYAs with knowledge regarding treatment options and the potential physical and QOL implications of cancer therapy	6.58	1 (tie)	6.59	6.57	0.91
Inform reproductive-age patients of cancer-related fertility risks as early in treatment planning as possible (per the ASCO guideline 24) and refer as needed to an appropriate fertility preservation specialist	6.58	1 (tie)	6.63	6.52	0.58
Provide access to a systematic and standardized symptom management, pain control, and palliative care program	6.5	2	6.7	6.24	0.01
Make survivorship care plans available to patients and other appropriate health care providers	6.27	3	6.26	6.29	0.90
Provide awareness, assessment, and support of practical issues while under treatment, such as childcare, transportation, and housing	6.23	4	6.41	6	0.09
Assist with navigation of financial and insurance issues when needed	6.21	5	6.19	6.24	0.83
Have educational programs that would increase healthcare provider knowledge of unique AYA issues related to psychosocial, legal, financial, genetic testing, palliative care, etc. needs	6.17	6	6.07	6.29	0.30
Provide resources for managing comorbidities and ongoing late effects	6.15	7 (tie)	6.41	5.81	0.02
Provide access to clinical interviews/psychosocial assessments to evaluate social functioning, sexual health, mental health status, religion and spirituality, psychiatric symptoms, cognitive functions, and financial/legal issues	6.15	7 (tie)	6.52	5.67	0.00
Assist AYA survivors in developing appropriate self-management behaviors, including health literacy, coping skills, and understanding of treatment implications	6.13	8	6.11	6.14	0.89
Provide or refer to resources for developmentally appropriate end-of-life care	6.1	9	6.52	5.57	0.01
Provide lifetime access to portable treatment records	6.06	10	5.78	6.43	0.01

CONCLUSION

Access to patient education programs, referral to a fertility preservation specialist and access to systematic and standardized symptom management, pain control and palliative care program were identified as top ranking QOL strategies by both Delphi panels.