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Young Adult Female Cancer Survivors' Unmet Information Needs and Reproductive Concerns Contribute to Decisional Conflict about Post-treatment Fertility Preservation

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Abstract

Background—Many young adult female cancer survivors (YAFCS) are at risk for premature menopause. This study characterized YAFCS' post-treatment fertility information needs, reproductive concerns, and decisional conflict about future options for post-treatment fertility preservation (FP).

Methods—Participants completed a web-based, anonymous survey between February and March 2015. The survey included investigator-designed questions of perceived information needs, the Reproductive Concerns after Cancer Scale (RCACS), and the Decisional Conflict Scale (DCS). Analyses included Pearson's correlations, t-tests, and multiple regression.

Results—Participants (N=346) averaged 29.9 years old (SD=4.1) and were 4.9 years post-treatment (SD=5.4; range, 0-27). Main analyses focused on a subgroup of YAFCS with uncertain fertility status who had not previously undergone/attempted FP and either wanted future children or were unsure (n=179). Across fertility information topics, 43-62% reported unmet information needs. The greatest reproductive concerns related to fertility potential and health of future offspring. The regression model controlled for a priori covariates including current age, age at treatment completion, income, relationship status, nulliparity, and prior fertility evaluation. Greater unmet information needs related to greater decisional conflict ($\beta=0.43$, $p<.001$); greater reproductive concerns were associated at the trend level ($\beta=0.14$, $p=.08$; $F[8,118]=6.42$, $p<.001$).

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Conclusions—YAFCS with limited awareness or knowledge of their risk for premature menopause and FP options report higher levels of decisional conflict about future FP. Post-treatment survivorship care should include comprehensive reproductive health counseling, including post-treatment FP options and family-building alternatives.

Keywords

cancer survivorship; reproductive health; fertility; fertility preservation; decision-making

An estimated 1 in 47 women will be diagnosed with invasive cancer as a young adult.¹ The gonadotoxic effects of many cancer treatments are well established, and providers are increasingly addressing fertility issues with their patients.^{2,3} However, most women do not pursue fertility preservation (FP) before treatment, despite wanting biological children in the future.^{3,4} Reasons include not being aware of fertility risks or FP options, time pressures, emotional distress, financial costs, and discomfort with the idea of using donor sperm for embryo freezing, in the period before egg freezing was available.^{5,6} Health care providers are also less likely to discuss fertility risks and FP with children and adolescents because of their focus on survival and the lack of non-experimental options prior to pubertal onset.⁷

For young adult female survivors not ready to start a family, post-treatment FP may be an option, but it is an underutilized service.⁸ Many survivors will indeed maintain reproductive potential after treatment but remain at risk for premature ovarian failure (early menopause), with a narrowed window of reproductive opportunity. Despite this, young adult survivors often do not receive recommended follow-up care regarding their reproductive health.⁹ Clinicians also self-report as feeling inadequately informed about cancer-related fertility issues and may underestimate patients' concerns or fail to recognize fertility as a priority.^{7,10} Fertility information is one of the most cited unmet needs among young adult survivors in pre- and post-treatment care.^{11,12} Lack of awareness of post-treatment fertility status and uncertainty about reproductive potential has been linked to reduced mental health and quality of life.^{13–15}

Research suggests variability in how female cancer survivors cope with uncertainty and distress related to potential fertility problems. Some women report that fertility concerns dominate their thoughts in survivorship and describe a preoccupation with the “missed opportunity” to have preserved their fertility prior to treatment along with anxiety and regret.^{16,17} Others minimize or avoid fertility-related thoughts in an effort to prioritize normality and reduce anxiety and grief.^{18–20} Based on research highlighting distress associated with *confirmed* infertility, survivors may be negatively affected if they experience premature menopause unexpectedly, without having the chance to consider their FP options.

For many women, the option to preserve fertility may be feasible and medically appropriate, making the decision “preference-sensitive,” based on personal values.^{21,22} These types of decisions often invoke decisional conflict, particularly when the likelihood of expected outcomes is not definite.²³ Retrospectively, most female cancer survivors report clinically significant levels of decisional conflict about pre-treatment FP decisions.^{5,24,25} The experiences of post-treatment survivors considering future FP, however, are not well understood.

A better understanding of how young women understand their reproductive health and make decisions about the FP options available to them after treatment is needed. This will help to promote informed, values-based decision-making; enabling survivors to take advantage of available reproductive technology when desired and appropriate, and avoid potential future distress. The goals of this study were to describe survivors' unmet information needs about fertility topics, their reproductive concerns, and the degree of decisional conflict they experienced when prompted to consider the decision to pursue FP in the future. In order to identify potential factors contributing to decision-making distress, the extent to which unmet information needs and reproductive concerns related to decisional conflict about future FP was also evaluated.

Methods

Design

Cross-sectional, internet-based survey designed to measure the fertility-related experiences of young adult female cancer survivors who had completed therapy. Surveys were administered between February – March, 2015. This study was approved as exempt research by the Memorial Sloan Kettering Cancer Center (MSK) Institutional Review Board.

Participants

Eligibility criteria included female survivors between the ages of 18 to 35 years old with a prior cancer diagnosis, who had successfully completed treatment at least one year prior, and were disease-free.

Survey

The survey was designed by an interdisciplinary team with input from young adult female survivors. The survey was anonymous and protected health information was not collected. Standard questions were used to assess sociodemographic, medical, and fertility-related information. Reasons for not pursuing FP before treatment were assessed using items derived from Kim et al.⁵ Participants responded yes/no to a list of factors shown to be important in the FP decision-making process with the option to select more than one (e.g., time constraints, emotional distress, and cost).⁵ The survey was administered online using a commercially available website with SSL encryption. Participants were recruited through MSK and 17 young adult cancer survivor advocacy groups, using social media and email listservs. These procedures are consistent with recommended use of social media in young adult oncology research^{26–28} and similar to previously published studies with this population.^{16,29} Respondents were required to answer screener items to confirm eligibility.

Unmet information needs—Investigator-designed questions (5 items) assessed unmet information needs about fertility topics. Participants indicated (yes/no) whether they had as much information as they wanted about risk of infertility, risk of early menopause, options to assess their fertility status, options to preserve their fertility, and options for alternative family-building. A total score was calculated by summing the items (yes=0, no=1; range 0-5) such that higher scores indicate greater unmet information needs (Cronbach's alpha=.81).

Reproductive concerns—The Reproductive Concerns after Cancer Scale (RCACS) is an 18-item, validated measure that includes six subscales (3 items each): Fertility Potential, Partner Disclosure, Child’s Health, Personal Health, Acceptance (reverse coded), and Becoming Pregnant.³⁰ Responses are on a 5-point Likert scale from “Strongly disagree” to “Strongly agree” with total scores ranging from 18 to 90. Mean total and subscale scores were calculated with higher scores indicating greater reproductive concerns (Cronbach’s alpha=.83).

Decisional conflict about future FP—The “low health literacy” version of the Decisional Conflict Scale (DCS) was used to assess four domains of personal uncertainty in making a healthcare decision. This version of the DCS was chosen as a precaution given the online format and anonymity of the survey prevented formal assessment of participants’ reading skills. Subscales include: feeling uninformed, unclear about values, unsupported in decision-making, and feeling uncertain about which option to choose.³¹ The DCS is valid and reliable,²³ and the most widely used measure of decision-making quality.³² The current study included 8 items of the 10-item scale and good internal reliability was demonstrated (Cronbach’s alpha=.84). Total possible scores range from 0 to 100 with higher scores indicating greater decisional conflict.

Statistical Analyses

Descriptive statistics characterized the sample and reasons for not undergoing pre-treatment FP. Differences among the most common diagnoses were examined using ANOVAs and chi-square. Main analyses excluded participants who reported infertility or inability to carry a pregnancy, did not want future children, or had previously attempted or undergone egg or embryo cryopreservation or ovarian transposition. Independent samples t-tests and Pearson’s correlations evaluated bivariate relations among unmet information needs, reproductive concerns, and decisional conflict about future FP in the remaining subgroup. A regression model examined how unmet information needs and reproductive concerns contributed to decisional conflict about future FP. *A priori* covariates included current age, age at treatment completion, income, relationship status, nulliparity, and prior fertility evaluation. Missing data was not replaced. Percentages that are not based on the total sample of N=346 are specified.

Results

Among 714 respondents who accessed the survey, 359 (50%) met eligibility criteria and 346 of eligible respondents (97%) completed the survey. Participants primarily resided in the United States (84%) and were from suburban (49%), urban (32%), and rural (10%) areas. Average age at survey completion was 29.9 years old (SD=4.1). Participants were a mean of 23.6 years (SD=7.5) at the time of treatment completion; 35 (10%) were less than 15 years of age at diagnosis. The most common diagnoses were lymphoma (23%), breast (20%), gynecologic (14%), and leukemia (13%) with lymphoma and leukemia patients being younger with a longer time since treatment than other disease groups. Sociodemographic and clinical/fertility information are provided in Tables 1 and 2, respectively.

Fifty-six women (16%) underwent FP pre-treatment; four underwent FP post-treatment; and three attempted FP post-treatment but were unsuccessful. Women reported multiple reasons for not having pursued pre-treatment FP. Most common reasons were not knowing about FP (30%), feeling too distressed or overwhelmed (29%), and/or cost (27%).

At the time of survey completion, 106 (31%) participants had been told that they will not be able to get pregnant or carry a pregnancy due to treatment effects; 21 (20%) of those women had preserved their fertility before treatment. Notably, 92% of this subgroup wanted children in the future. Gynecologic and leukemia survivors were more likely to be infertile, but differences in relationship status, nulliparity, or prior fertility evaluation were not significant across disease groups.

Subgroup analyses

The primary subgroup of interest was women who wanted children in the future or were unsure, had not been told they were infertile, had not undergone ovarian transposition, and had not previously attempted or undergone egg or embryo cryopreservation. The following analyses were conducted in this subgroup ($n=179$; see Tables 1 and 2 for descriptive data).

Regarding *unmet information needs*, most respondents felt they did not have enough information on infertility risk (58%), early menopause risk (60%), options to assess their fertility (62%), options to preserve their fertility (51%), and options for alternative family-building (43%). The greatest *reproductive concerns* ($M=3.20$, $SD=0.65$) were related to concerns about potential fertility problems and health of a future child. For example, 64% were concerned they may not be able to have (more) children, 41% reported it was stressful to think about getting pregnant, and 59% were worried about passing on a genetic risk for cancer. Potential interpersonal difficulties were also indicated; 53% of women were concerned their partner or a future partner would be disappointed if they were unable to have children.

When prompted to consider the option of pursuing FP in the future, participants indicated high levels of *decisional conflict* ($M=61.09$, $SD=24.88$). Only 13% felt informed about their FP options and 74% were unclear about their personal values related to the decision. Notably, 70% felt they did not have enough advice, and 35% felt they did not have enough support to make a decision.

In bivariate analysis, greater decisional conflict was associated with having greater unmet information needs (Information Needs total, $r=.47$, $p<.001$) and reproductive concerns (RCACS total, $r=.26$, $p=.001$). Across all information topics, women who indicated that they had unmet information needs reported higher levels of decisional conflict (Figure 1; $p<.01$).

In multiple regression analysis controlling for current age, age at treatment completion, income, relationship status, nulliparity, and prior fertility evaluation, the relation between greater unmet information needs ($\beta=0.43$, $p<.001$) and higher levels of decisional conflict about future FP remained significant; greater reproductive concerns were associated with greater conflict at the trend level ($\beta=0.14$, $p=.08$; $F[8,118]=6.42$, $p<.001$). Having undergone a fertility evaluation post-treatment related to lower decisional conflict ($\beta=-0.19$, $p=.02$).

Unmet information needs and reproductive concerns accounted for 22% of the variance in decisional conflict ($F_{change}[2,118]=18.79, p<.001; R^2_{total}=.30$). See Table 3.

Discussion

Many young adult female cancer survivors report a desire for biological children in the future but, for a variety of reasons, are unable to undergo FP prior to treatment. Those who maintain reproductive capacity after treatment, but are at risk for premature menopause, may have a second opportunity to pursue FP. This study is the first to our knowledge to examine the decisional conflict of young female survivors' when prompted to consider *post-treatment* FP. For those who hope to have children in the future, failure to provide information and address concerns with respect to fertility-related decisions may have lasting consequences for their future family-building options.

Consistent with existing literature, we report high rates of unmet fertility information needs and reproductive concerns.^{11,12,33} To best inform clinical practice, we focused on the subgroup of women who had not been told they were infertile, believed they may want children in the future, and had not previously undergone FP. This subgroup of women reported high levels of decisional conflict about future FP. In other healthcare contexts, decisional conflict is associated with greater emotional distress, future decision regret, and greater likelihood of blaming providers.³⁴ Unmet information and support needs increase decisional conflict and the risk for regret and distress.³⁵⁻³⁸ Women who receive pre-treatment fertility counseling experience less regret and report better quality of life post-treatment.^{17,39,40} However, fertility counseling alone may still result in low knowledge about fertility issues,^{41,42} suggesting more comprehensive approaches to providing decision support may be warranted.

Decisional conflict is also associated with an increased likelihood of avoiding or delaying decisions.³⁴ Quinn et al. found that adolescent female survivors used a range of strategies to cope with potential fertility loss, including avoidance and denial of distressing cognitions.¹⁹ Notably, all of the adolescents in their sample reported a desire for biologic children, but neither they nor their parents were aware of the adolescents' fertility status.¹⁹ Likewise, survivors have also reported a desire to postpone addressing fertility issues until they were ready to have children.⁴³ Women who delay decision-making about FP may lose the option to take advantage of reproductive technologies and preserve their fertility post-treatment, if desired.

Importantly, decisional conflict may arise from multiple sources, and there may be subgroups of survivors with greater or different types of decision support needs. Providing information and addressing misperceptions about fertility topics is an important first step for all survivors, regardless of medical factors. In this survey, 71% of those queried worried about their family health history affecting future children, independent of a hereditary cancer diagnosis. Young survivors also report reproductive concerns while concurrently acknowledging their oncologists' reassurance otherwise.⁴³ Periodic assessment of survivors' level of understanding about reproductive health issues and the nature of their concerns will help guide clinical practice and potentially avoid or ameliorate fertility-related distress.

Importantly, ovarian function should be monitored irrespective of survivors' desire for future children as lack of estrogen resulting from ovarian failure may exacerbate other late effects of cancer treatment such as cardiotoxicity, bone health, and endocrine disorders.⁴⁴

Limited evidence suggests decision aids and counseling improve patient decision-making about *pre-treatment* FP and reduce later regret.^{24,38} However, factors influencing post-treatment FP decisions are different from pre-treatment decisions. Decision support needs may differ as women move beyond the emotional, physical, and financial aftermath of their cancer experience and fertility-related treatment effects are more fully realized.^{45,46} After treatment, survivors have more time to clarify their options, consider personal values and priorities, access support, and gather financial resources. Further work should determine the types of resources women need and the best approaches to provide those resources. While it is clear that information should be provided, additional efforts may help those who are highly distressed, anxious, or avoidant. A stepped care model of support may best address the varying levels of support needs by providing the opportunity for women to "step up" to increasingly supportive resources as needed (e.g., decision aid plus decision counselor).

It is also critical that reproductive health counseling be comprehensive. In addition to FP, support services should address alternative paths to achieving motherhood. We found that only a minority of the women (20%) who were unable to become pregnant or carry a pregnancy had preserved their fertility, despite 92% wanting future children. Forty-three percent reported unmet information needs regarding alternative family-building options such as adoption. Contraceptive use and counseling around safe sexual practices is equally important.⁴⁷ Addressing issues related to dating and disclosure may also help survivors navigate interpersonal difficulties.³³ Fertility topics affect a range of psychosocial concerns among young survivors and support services are sorely lacking.⁴⁸

While the use of social media and web-based procedures have been recommended when conducting research with young adult cancer survivors,^{26,27} a number of limitations must be considered. Although screening items assessed eligibility, participant responses were not externally validated. Recruitment using young adult cancer advocacy groups' social media outlets may have compromised the generalizability of the findings. Additionally, the cross-sectional design precluded conclusions regarding causality. Analyses were driven by empirically-based decision-making research,^{34,49} but further work is needed to determine the directionality of relations. Longitudinal studies may identify changes in survivors' decisional conflict and support needs as they age with shifting priorities and life goals. Despite these limitations, findings fill an important gap in the literature regarding young adult female survivors' decision-making about FP *after* treatment. The relatively large sample size and geographic diversity of the sample are important study strengths.

Conclusions

These data underline the importance of addressing fertility issues in post-treatment survivorship care to ensure that women at risk for premature ovarian failure do not miss their narrowed window of reproductive opportunity. There is a critical need to develop resources for survivors and for clinicians to use to support patients in making informed, values-based

decisions about their reproductive options. This should be done in parallel to research addressing other sources of survivors' unmet needs and barriers to clinical implementation of interventions (e.g., providers' lack of knowledge or prioritization of fertility). Research supporting the use of biomarkers such as anti-Müllerian hormone to predict post-treatment reproductive potential is also growing with great promise of improving patient counseling.⁵⁰ While patients will certainly benefit from more personalized information, this alone is not likely to eliminate decisional distress as women must still determine how their unique values, preferences, and circumstance weigh against the pros and cons of treatment options.³⁴ Research prioritization strategies may be used to identify the relative value of targeting different approaches to improving patient outcomes, alone or in combination, and to ensure efficient use of research resources.⁵¹

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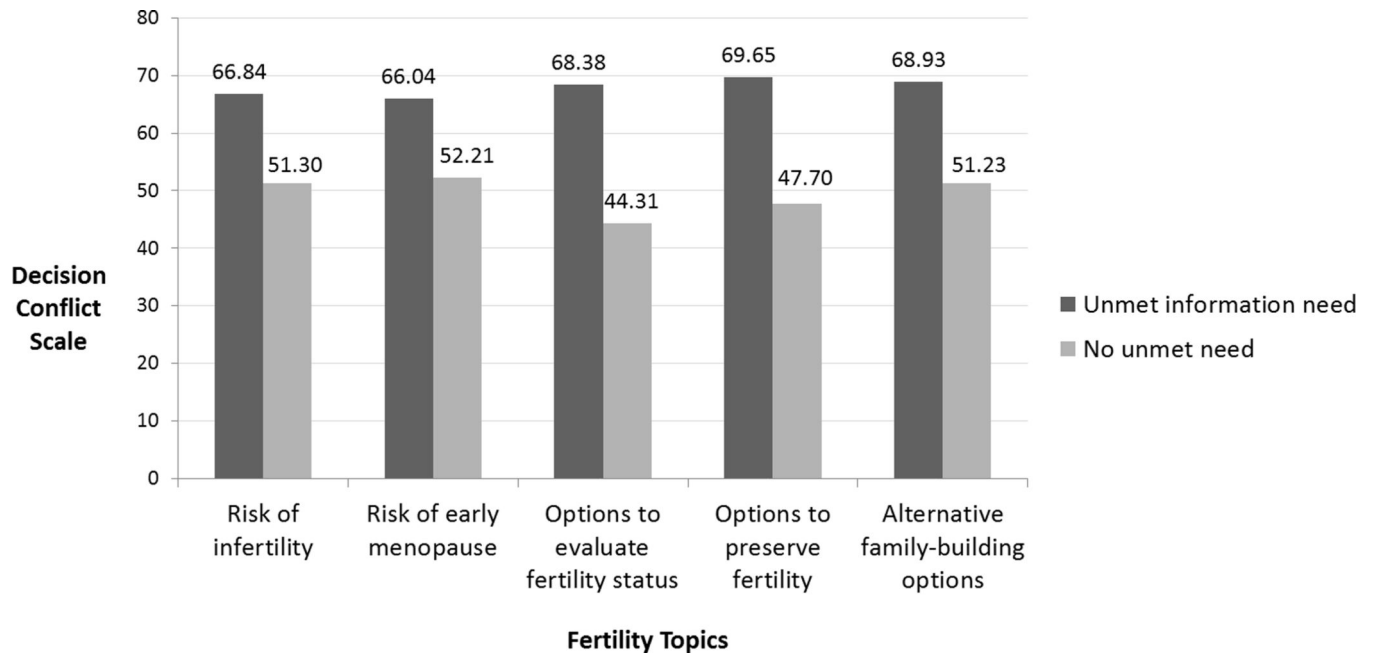


Figure 1. Unmet information needs about fertility topics is associated with greater decisional conflict about future fertility preservation

Participants who reported unmet information needs about fertility topics reported significantly higher levels of decisional conflict about future fertility preservation (independent samples t-tests; all p 's < .01). Mean levels of decisional conflict for subgroups with and without unmet information needs are depicted.

Table 1

Sociodemographic characteristics of the total sample (N=346) and subgroup (n=179).

Sociodemographics	Total Sample			Subgroup ¹		
	M (SD), range	n	%	M (SD), range	n	%
Age at survey completion (years)	29.9 (4.1), 18–35			29.5 (4.2), 18–35		
Age at diagnosis (years)	23.6 (7.5), 0–35			23.4 (7.1), 0–34		
< 15 years at diagnosis		35	10		19	11
Race						
White		279	81		140	78
Other		29	8		13	7
Hispanic ethnicity		25	7		10	6
Education						
< College degree		76	22		35	20
College degree		241	69		121	68
Enrolled student, full or part-time		74	21		37	21
Employed, full or part-time		249	72		125	70
Household income (annual; U.S. dollars)						
<50,000		103	30		52	29
50,000 – 100,000		116	34		59	33
>100,000		77	22		34	19
Married or living with a partner		208	60		106	59
Had at least 1 child		109	31		50	28

¹ Subgroup that had not been told they were infertile or unable to carry a pregnancy, who had not previously undergone egg/embryo cryopreservation or ovarian transposition, and who wanted future children or were unsure.

Table 2

Clinical and fertility information of the total sample (N=346) and subgroup (n=179).

Clinical information	Total Sample		Subgroup	
	n	%	n	%
Cancer diagnosis				
Lymphoma	79	23	50	28
Breast	68	20	31	17
Gynecologic ²	50	14	20	11
Leukemia	45	13	15	8
Colorectal	27	8	10	6
Sarcoma	23	7	11	6
Brain	13	4	7	4
Other	54	16	35	20
Gonadotoxic treatment				
Pelvic radiation	59	17	13	7
Chemotherapy	285	82	141	79
Surgery	36	10	5	3
Bone marrow transplant	35	10	4	2
Time since treatment ended (years)				
< 2	113	33	56	32
2 – 5	133	38	72	40
> 5	98	29	50	28
Fertility information				
	Before Treatment			
	n	%		
Fertility preservation history ³				
Egg or embryo cryopreservation	35	10		
Ovarian tissue cryopreservation	4	1		
Ovarian transposition	3	1		
Ovarian suppression	16	5		
Other type of FP	4	1		
Total	56	16		

¹ Subgroup that had not been told they were infertile or unable to carry a pregnancy, who had not previously undergone egg/embryo cryopreservation or ovarian transposition, and who wanted future children or were unsure.

² Includes ovarian, cervical, and uterine cancers.

³ Fertility preservation options were not mutually exclusive.

Table 3

Regression model predicting decisional conflict about future fertility preservation (n=179).¹ Greater decisional conflict about future fertility preservation was associated with greater unmet information needs and, at a trend level, greater reproductive concerns. Unmet information needs and reproductive concerns accounted for 22% of the variance in decisional conflict.

Dependent Variable: Decisional Conflict Scale (F[8,118]=6.42, p<.001)						
Step	Variable ²	R ²	B	SE	β	t
1	Constant	.08	27.19	16.84		
	Current age		-.30	.61	-.05	-.49
	Age at treatment completion		.46	.38	.12	1.20
	Relationship status (0=single)		-4.87	4.71	-.10	-1.03
	Nulliparity (0=no children)		4.90	4.97	.09	.99
	Annual income (0=less than 50k)		.45	4.38	.01	.10
	Fertility Evaluation (0=no evaluation)		-15.29	6.31	-.19	-2.42
2	Unmet Information Needs		5.45	1.05	.43	5.19
	Reproductive concerns		.30	5.49	.14	1.74

¹ Subgroup that had not been told they were infertile or unable to carry a pregnancy, who had not previously undergone egg/embryo cryopreservation or ovarian transposition, and who wanted future children or were unsure.

² The dichotomized variables include: relationship status (0=single; 1=partnered/married), nulliparity (0=no children; 1=at least one child), annual income (0=less than \$50,000, 1=greater than/equal to \$50,000), and fertility evaluation (0=no evaluation since treatment completion, 1=had an evaluation post-treatment).