



Factors influencing the documentation of fertility-related discussions for adolescents and young adults with cancer

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ABSTRACT

Purpose: A cancer diagnosis and treatment may have significant implications for a young patient's future fertility. Documentation of fertility-related discussions and actions is crucial to providing the best follow-up care, which may occur for many years post-treatment. This study examined the rate of medical record documentation of fertility-related discussions and fertility preservation (FP) procedures for adolescents and young adults (AYAs) with cancer in Australia.

Methods: A retrospective review of medical records for 941 patients in all six Australian states. Patients were identified through population-based cancer registries (four states) and hospital admission lists (two states). Trained data collectors extracted information from medical records using a comprehensive data collection survey. Records were reviewed for AYA patients (aged 15–24 years at diagnosis), diagnosed with acute myeloid leukaemia, acute lymphoblastic leukaemia, central nervous system (CNS) tumours, soft tissue sarcomas (STS), primary bone cancer or Ewing's family tumours between 2007 and 2012.

Results: 47.2% of patients had a documented fertility discussion and 35.9% had a documented FP procedure. Fertility-related documentation was less likely for female patients, those with a CNS or STS diagnosis and those receiving high-risk treatments. In multivariable models, adult hospitals with an AYA focus were more likely to document fertility discussions (odds ratio[OR] = 1.60; 95%CI = 1.08–2.37) and FP procedures (OR = 1.74; 95%CI = 1.17–2.57) than adult hospitals with no AYA services.

Conclusions: These data provide the first national, population-based estimates of fertility documentation for AYA cancer patients in Australia. Documentation of fertility-related discussions was poor, with higher rates observed in hospitals with greater experience of treating AYA patients.

1. Introduction

The risk to fertility from a cancer diagnosis and treatment is of high importance to young people (Benedict et al., 2016; Palmer et al., 2007;

Tschudin and Bitzer, 2009) and a lack of information around fertility has been identified as a key unmet need (Olsson et al., 2015). International guidelines for the treatment of adolescents and young adults (AYAs) with cancer emphasise the need for health care professionals

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(HCPs) to discuss the gonadotoxic risks of cancer treatment before commencement (Clinical Oncological Society of Australia, 2011; Loren et al., 2013; National Institute for Health and Care Excellence, 2013). However, studies have reported sub-optimal rates for these discussions, with only 59%–63% of patients/oncologists reporting infertility risk discussions and 18%–31% of patients reporting discussions about fertility preservation (FP) options (Anderson et al., 2008; Armuand et al., 2012). A survey of AYAs with cancer attending a patient conference in the United Kingdom (UK) in 2004 found that only 36% of respondents recalled being told the risk to their fertility before commencing treatment (Smith et al., 2007).

Oncofertility consultations not only provide patients and their families with the opportunity to make FP choices, but also link them to specialists who can provide care for current and future reproductive issues such as complex contraceptive management, infertility, menopause and sexual dysfunction. If these discussions or consultations are not documented, important oncofertility information may not be communicated to patients and HCPs during treatment and follow-up care.

A review of AYA medical records at four treatment centres in the United States (US) found that infertility risk discussions were documented for only 26% of patients, with FP discussions documented for 24% (Quinn et al., 2015). Furthermore, only 13% had a referral to a fertility specialist documented (Quinn et al., 2015). Similar rates of fertility discussions have been reported in recent Canadian (Kumar et al., 2012) and US (Grover et al., 2016) studies (34% and 29%, respectively), though higher rates have also been reported. A rate of 83% was reported by Salsman et al. (2016) who reviewed medical records of patients attending a comprehensive cancer centre with a dedicated model of care for fertility-related decision-making. Similarly, Lewin et al. (2017) reported documentation rates of 85% for fertility risks and 86% for FP options, post-implementation of an AYA program at one Canadian treatment centre. These higher rates of documentation in past studies may exemplify the benefits of targeted programs to ensure fertility is discussed. However, population-based studies provide a more accurate picture.

The age range defining adolescence and young adulthood also differs internationally. In Australia and the UK adolescence and young adulthood is commonly defined as ages 15–24, while in the US it is more commonly defined as ages 15–39. Cancer patients and survivors aged 25–39 may have very different life experiences than those aged under 25, particularly in regards to having had, or trying to have children. The experiences of American AYAs therefore may not generalise to AYAs in countries using a younger upper age limit. Information on rates of fertility discussions and referrals from other countries is needed.

The current study examines the level of documentation, and the factors associated with the documentation of fertility-related discussions and FP procedures in the medical care of AYAs (15–24 years) with cancer. This study involved a retrospective review of patient medical records in all Australian states, providing the first national examination of this issue for this age group.

2. Method

2.1. Design and participants

Retrospective review of medical records for AYAs diagnosed with one of five cancer types: acute myeloid leukaemia (AML), acute lymphoblastic leukaemia (ALL), central nervous system (CNS) tumours, soft tissue sarcoma (STS), primary bone cancer and Ewing's family tumours (EFT); cancers with 5-year survival rates between 61 and 77%, lower than the overall rate for AYA cancer of 88% (Australian Institute of Health and Welfare, 2011). AYAs were from all six Australian states.

Eligible patients were identified through the population-based cancer registries (CRs) in four states and through hospital admission lists in two states. Patients were eligible if they were permanent

residents in a participating state, were aged 15–24 years when diagnosed, with a primary diagnosis of one of the specified cancers between 1/1/2007 and 31/12/2012. For each case, the CRs in each state identified all notifying hospitals.

2.2. Data collection

A comprehensive data collection tool was developed and pilot tested in one state for feasibility and time needed to extract data. Trained data collectors attended hospitals to extract information from electronic and paper-based medical records. If a patient attended multiple hospitals during their cancer care, treatment details were sought from each site. Where information in the record was unclear/incomplete, further information was sought from the local clinical contact.

2.3. Data extraction

Detailed diagnostic and treatment information was extracted including: demographics, mode of presentation, diagnostic and staging investigations, first-line treatment and relapse. Fertility information included whether a fertility *discussion* had been documented (Yes/No), whether a FP *procedure* had been documented (Yes/No) and, if so, what this procedure was. Information on further fertility-related action documented in the record was also recorded. Treatment information included the site of surgery, radiotherapy site and dose, chemotherapy drugs and dosage, and whether a bone marrow transplant occurred. Whether a patient's treatment posed a risk to their fertility (no/low, intermediate, or high) was determined according to prescribed risk factors and guidelines from the LiveStrong fertility risk calculator (<https://www.teamlivestrong.org/we-can-help/fertility-services/risks/>), the Children's Oncology Group (<http://survivorshipguidelines.org/>) and Levine et al. (2010).

Age, sex and residential postcode were recorded. Postcode was used to determine socio-economic status (SES) using the area-based Socio-Economic Indexes for Areas (Australian Bureau of Statistics, 2013) which ranks postcodes from most to least disadvantaged. Patients' residence and hospital were categorised as metropolitan or regional based on postcode, using the Greater Capital City Statistical Areas (Australian Bureau of Statistics, 2011).

The number of patients attending each hospital over the study period (2007–2012) was used to calculate hospitals' AYA caseload for the selected diagnoses. Hospitals having an AYA-focussed approach to care were defined as those providing medical and psychosocial services tailored to AYA patients, including HCPs experienced in AYA care and a commitment to professional development and training for the treatment of this cohort. Services that linked patients to a specialist AYA service were included in this definition. AYA treatment centres were identified in consultation with clinicians from each state, and were generally located in major cancer treatment centres. 26 adult centres and 9 paediatric centres were classified as an "AYA centre" according to this definition.

Survival information was obtained from the Australian National Death Index provided by the Australian Institute of Health and Welfare. Ethical approval was obtained from Human Research Ethics Committees in each state (White et al., 2016).

2.4. Statistical analysis

The associations between documentation of fertility-risk discussions and FP procedure and demographic, diagnosis and treatment-related factors were examined using logistic regression. Characteristics associated with fertility documentation at $p < .10$ in univariate models were retained for multivariable models (Hosmer and Lemeshow, 2000). As AYA-focussed centres necessarily treated a higher caseload of AYA patients, only the treatment centre was included in multivariable models. Analyses were conducted in SPSS v.20.

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