

Clarification of Self-Reported Family History Data by Telephone Interview

Nina Kadan, Debra Friedman, Ann Mertens, Yutaka Yusui, John Whitton, Leslie Robison, Louise Strong, University of Minnesota, Minneapolis, MN; University of Washington, Seattle, WA; Fred Hutchinson Cancer Research Center, Seattle, WA; University of Texas M.D. Anderson Hospital, Houston, TX.

Introduction: As part of the Childhood Cancer Survivor Study (CCSS), cancer history in first-degree relatives was obtained from 13,976 long-term childhood cancer survivors. Data were collected by an identical questionnaire read by phone (32%) or sent by mail (68%), resulting in 2395 reported cancers in 69,756 family members. We investigated whether a probing follow-up phone interview could clarify conditions for which site and malignancy status were uncertain from the original survey. **Methods:** A panel of pediatric oncologists, cancer epidemiologists, and cancer geneticists independently reviewed the reported cancers from the CCSS questionnaires. By consensus, the histories of 535 of the 2239 first-degree relatives with a reported cancer condition required additional clarification to assign SEER diagnosis codes. The proportion of initial questionnaires done by telephone vs. mail in this subgroup was similar to the entire cohort. The responses requiring clarification were suggestive of one or more of the following potential sources of error: citing a metastatic site as the primary site, mistaking a benign for a malignant condition, reporting metastatic sites as separate primary cancers, and lack of detail in site or histology. Individualized phone clarification scripts were composed for these 535 individuals (relatives of 501 CCSS cases) and administered by trained interviewers to the CCSS cases. Information requested included specific names of the condition(s), organs of involvement (including origin), therapies, and malignancy status. **Results:** Preliminary data on 336 of the 535 individuals with 414 reported ambiguous conditions resulted in 83% of conditions being satisfactorily clarified in terms of both site of disease and malignancy status, as concluded by three members of the research panel who individually reviewed the completed surveys. We identified 254 invasive cancers, 45 benign tumors, 41 tumors with indeterminate malignancy status, and 20 non-neoplastic conditions. Sites most frequently reported as primary but clarified as metastatic included liver (10/25), brain (6/13), bone (10/13) and lung (4/20). Clarification of reported multiple primary cancers indicated that 49 of 72 individuals had only a single cancer with metastatic sites or synonymous names. Of 130 reported "carcinomas" and "cancers," not further specified, 95 were determined to be malignant (83 with known primary site) and 35 to be benign or non-neoplastic diseases. 38 of 69 cancers reported as "tumor" or "tumor of body part" were clarified to a SEER-classified malignant site. **Discussion:** A detailed follow-up clarification phone survey is a feasible and useful method to obtain additional information on self-reported cancer family history data of first-degree relatives. Adding probing questions regarding the name, site, and treatment of reported cancers to the initial questionnaire may obviate the need for later clarification.