

Sun Exposure Recall: Instrument Development and Evaluation

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Abstract

Although epidemiologists recognize misclassification arising from imperfect recall as a serious problem, their use of cognitive methods and theory in questionnaire design is recent and infrequent. While early-life sun exposure is an important risk factor for malignant melanoma, the relevant amount of exposure and the effect of pattern (constant versus intermittent) are unknown. We developed an early-life sun exposure instrument through interviews with key researchers, focus groups, cognitive interviews, and field pretesting, and assessed (with a field test on melanoma patients and population controls) its response completeness, test-retest reliability and the effect of these on odds ratio estimates. Interviews with key researchers emphasized the importance of specific local sun-related behaviors, techniques for cognitive interviewing and reliability testing, and ideas for revising a life event calendar to provide a framework for recall. Focus groups provided important cues to recall, including best friends, unusual burns, summer activities, vacations, and sunburn treatments (both novel and familiar). Results of cognitive interviewing, pretesting and the field test will be presented. Our methods and findings are relevant for etiologic studies of other conditions with important early-life exposures.

1. Introduction

Malignant melanoma, the most serious type of skin cancer, is the second most common cancer among young adults aged 20-44, and its incidence is increasing (Marrett *et al.* 2002). Sun exposure in early life, especially sunburns, appears to be an important risk factor for malignant melanoma (Armstrong 1997). It has been hypothesized that both the amount and the pattern of sun exposure (intermittent versus constant) are important (Armstrong and English 1996). Few studies, however, have examined the role of early life sun exposure in developing melanoma, and the results have been inconsistent (Elwood and Jopson 1997).

Epidemiologists are interested in improving the measurement of exposure to factors associated with disease risk. While they recognize the impact of poor comprehension of questions and incomplete recall on study results, their use of cognitive methods and theory when designing questionnaires is relatively recent and infrequent (Friedenreich 1994). More prevalent are the traditional methods of brainstorming based on expertise, literature review, assessment of existing questionnaires, consultation with other investigators, pretesting on friends and colleagues, and some attention to clear language and design. Usually, limited pilot testing is done in target populations. There is a knowledge transfer gap which needs to be addressed, especially in light of increasing evidence that incorporating different techniques helps to develop more robust measurement tools (O'Brien 1993, Ing *et al.* 2002, Theis *et al.* 2002). Recall of sun exposure is considered particularly difficult, since people are being asked to remember an aspect of their childhood routines that may not be easily retrieved from autobiographical memory. As well, respondents are asked to perform complex processing of information in order to provide an estimate of how long they were outside in the sun (Forsyth *et al.* 1992).

In order to better measure the relationship between early life sun exposure and melanoma, we decided to use a variety of methods to develop a new questionnaire that would improve recall and allow the examination of sun exposure patterns. Since this development work required experts in the areas of epidemiology, behavioural science, survey design, and qualitative research techniques, we assembled a team with complementary skills and experience.

The questionnaire developed through this project is intended for use in epidemiological studies. In particular, the case-control design is often used to investigate the relationship between disease (skin cancer) and exposure (sun). In a case-control study, exposure information is collected from a sample of people with the disease of interest (cases) and a similar sample of people chosen randomly from the population who do not have the disease (controls). Since the link between sun exposure and skin cancer has been well publicized in recent years, it is likely that cases have thought more about their early life sun exposure than controls. It is important, therefore, to include both groups in all information gathering and testing phases of the questionnaire's development.

2. Methods

2.1. Preliminary Work

Since some members of the project team had not previously used qualitative methods to develop questionnaires, time was spent in 1999 learning about techniques such as focus groups and cognitive interviewing, and how they could contribute to the design process, as well as identifying experts to augment the team's skill base. Books such as *Answering Questions, Constructing Questions for Interviews and Questionnaires* and *Measurement Errors in Surveys* proved useful (Foddy 1994, Biemer *et al.* 1991, Schwartz and Sudman 1996). Papers in refereed journals and conference proceedings covering many fields were reviewed (Bradburn *et al.* 1987, Schechter *et al.* 1991, Willis *et al.* 1991, Willis *et al.* 1992, Hatch *et al.* 1999). From this body of literature, and using the experiences and expertise of the study team, a grant proposal for developing and testing a questionnaire focusing on early life sun exposure in young melanoma cases and population controls was written, submitted and funded by the US National Cancer Institute.

2.2. Key Informant Interviews

Key informant interviews were conducted to assist the questionnaire development phase. As Gilchrist describes, key informants are purposefully selected because they are knowledgeable about the area of investigation, are able to articulate this knowledge effectively and thus inform many aspects of the study (Gilchrist 1992). Semi-structured interviews

were conducted to gather information from key informants about how they developed their questionnaires, study methods, what worked well and what they would do differently in the future.

Four key informant interviews were conducted between October 1999 and January 2001. The first was with Drs. Bruce Armstrong and Anne Kricker, melanoma researchers in New South Wales, Australia. They were the original designers of a life events calendar and questionnaire used in several studies (Kricker *et al.* 1995). The second interview was with Dr. Christine Friedenreich, Alberta Cancer Board. She used a variety of techniques, including cognitive interviews, to develop a recall calendar to help women remember early life physical activity (Friedenreich *et al.* 1998). Dr. Phillippe Autier, currently with the European Agency for the Development and Health, was interviewed next. In Europe, sun exposure tends to be more intermittent than in Australia, so the questionnaire he helped to develop concentrated on childhood residence history and vacation history (Autier *et al.* 1998). Lastly, we spoke to Dr. Margaret Karagas of New Hampshire, who adapted the Australian questionnaire for use in North America (Lichter *et al.* 2000).

2.3. Focus Groups

Focus groups contribute to questionnaire development in two major ways: they can inform researchers about appropriate wording for questions and responses; more fundamentally, they can provide an understanding of what the project means to members of the study population. The group process allows investigators to hear the contrasting viewpoints that become evident when group members react to one another's comments. It can enhance the validity of quantitative questionnaires by generating ideas and themes that might not occur to investigators, and may result in new questionnaire items (Morgan and Kreuger 1993, Kindree *et al.* 1997).

The goal of the focus groups was to explore participants' ways of thinking and talking about their early life sun exposure. Some of the specific questions to be answered included how far back they could recall outdoor activities, and what memory triggers or cues they used to help with recall. The control participants were recruited by York University's Institute for Social Research (ISR) (Northrup 1997). Participants were provided with a package of materials to prepare them for the focus group. The materials included a

cover letter describing the study, a copy of the questions to be asked during the session, a background questionnaire and two copies of an informed consent form (one to sign and remit at the group; the other to be retained by the individual for his/her personal records).

Three focus groups were held between March and April 2001. One group consisted of four melanoma cases, while the other two were sampled to represent lower and higher SES population groups. Focus groups were conducted by two of the project team members (JF, FA), and were held in local libraries. The groups were balanced for men and women. Most participants spent their childhood in urban settings; only one came from a rural environment. All participants lived in Toronto at the time of the focus group. They were paid a modest honorarium to defray travel and related expenses to attend the group, and the focus groups were taped (with participants' permission), transcribed and analyzed.

2.4. Design of Draft Instrument

During the summer of 2001, four project team members (DN, BT, JF, LM) used the information from the key informant interviews and the focus groups to design a questionnaire to collect detailed information about early life sun exposure and facilitate recall of salient events such as sunburns. Meetings with the other team members helped by revealing potential problems. In September, naïve readers reviewed the questionnaire prior to alpha testing.

2.5. Alpha Testing

In the earliest stages of questionnaire design, a test using convenience samples can be helpful. Respondents can be selected to represent different situations, tend to be cooperative and the reliability of their answers can often be verified.

Three pretests were done in October 2001 with researchers' family members. The same researcher (JF) conducted each interview, while a supporting researcher (DN, BT) made notes about problems encountered. Neither the interviewer, nor anyone present at the time of the interview, knew the interviewee. One subject had received some of his education outside Canada. The second subject had been home-schooled, while the third

subject attended seven different schools. They covered a range of ages, both sexes and different after-school interests and summer jobs. The interviews were conducted over the phone and replicated the conditions planned for the final testing. Each interview provided encouraging results, but showed the need for revisions to capture a wider range of experiences. These revisions were then tested on two experienced ISR interviewers.

2.6. Cognitive Interviews

Research on the question-answering process suggests a four-stage cognitive procedure: question comprehension and interpretation, information retrieval, estimation and judgment about how to respond, and response formulation (Durante and Ainsworth 1996). Cognitive interviewing - asking participants to paraphrase questions and think aloud about their response processes - draws on the four-stage question-answering model described above.

We used the retrospective think-aloud approach to cognitive interviewing, in which the interviewer asks the respondent about the questionnaire completion experience immediately after finishing a set of questions (“Tell me what you were thinking about...”), and then uses targeted probes (“What do you think that question was asking about?”, “Why did you say that...?”) (Willis *et al.* 1991, Schaeffer and Maynard 1996, Harris-Kojetin *et al.* 1999). Retrospective questioning has the advantage of not altering the natural interview condition and is not as reliant on the respondent’s cognitive ability as other approaches (Forsyth *et al.* 1992, Bolton and Bronkhorst 1996, Bickart and Felcher 1996).

Members of the project team (JF, FA) conducted individual cognitive interviews with three cases and seven population controls. Among the 10 participants, there were three males and seven females. Four participants were between the ages of 20 and 29, three participants were 30-39 years old, and three were 40 years of age or older. Each participant was mailed a draft of the materials planned for the formal pretest. Each interview began as scripted for the formal pretest, but the full interview was not completed. Instead, retrospective questioning was used in one of each relevant cycle.

2.7. Formal Pretest

In the formal pretest phase, the questionnaire is administered under the conditions and procedures planned for the full study. Starting with a small sample, however, offers more opportunity to monitor interviews, debrief study staff, identify problems and make corrections or revise procedures before the study shifts into high gear. For the formal pretest, 20 cases and 20 controls were recruited. Between April and June 2002, 9 cases and 6 controls were interviewed.

2.7.1. Cases

Cases of malignant melanoma in young adults aged 20-44 were identified through pathology reports forwarded to the Ontario Cancer Registry (OCR) (McLaughlin *et al.* 1991). Approval to contact these cases must be obtained from physicians involved with their treatment. If physician consent was obtained, a case's address and phone number were requested, and a package of study material was sent to his/her home. The package consisted of the following:

- introductory letter
- background questionnaire
- blank life event calendar for the respondent
- flyer with three sample biographies, including the life event calendar as completed by the fictitious respondents
- examples of outside activities to assist recall
- sheet asking for preferred interview times
- stamped return envelope

Follow-up procedures were not in place for the pretest, and a variety of methods were tried. When the material was returned, one of the available interviewers was assigned to contact the case, set an interview time and conduct the interview.

2.7.2. Controls

Population controls were recruited across Ontario through random digit dialing by ISR. Numbers of men and women are matched to the sex/age distribution expected for the cases. Since skin cancer is rare in non-Caucasians, these individuals are identified with a screening question. When eligible controls agreed to participate, their address and phone number were obtained and the same mail and contact procedures described for cases were followed.

2.8. Test/Retest with Cases and Controls

Power calculations done for the test/retest protocol require two completed interviews with 125 cases and 125 controls. Based on previous experience with physician and respondent refusal rates, we will need to recruit 345 cases and 320 controls. After approximately four months, all cases and controls will be contacted again and the entire data collection and interview will be repeated. The final questionnaire will be evaluated by examining the completeness of responses, the test-retest reliability of the data and the odds ratios calculated for a case-control study.

3. Results

3.1. Key Informant Interviews

The use of life event calendars was considered essential by the Australian and North American researchers. One of the most important issues identified was the division of the age span into homogenous time periods when activities are similar. This makes it easier for respondents to recall outdoor activities and report when they occurred, how long they lasted, whether they wore clothing or sunscreen and whether they had been sunburned. While the early Australian calendars allowed many small time slices, the current version of their calendar asks only about sun exposure at ages 10, 20, etc. Karagas and colleagues used five lifetime behaviour change-points while Friedenreich and colleagues allowed different time periods for occupational, household and exercise/sports activities.

Informants observed that North Americans have different sun behaviors from Australians and Europeans, and that local habits, such as summer cottages and typical holiday patterns, need to be taken into account.

3.2. Focus Groups

Unfortunately, the sampling by socio-economic status was not very successful; the people willing to attend the focus groups did not reflect the income profiles of their neighbourhoods.

Several categories of important triggers were identified. Some had been anticipated, while others resulted from interaction between the facilitators and participants. General activities, such as playing outside and playing sports, and more specific activities, such as soccer, hiking, watching sports, camping and swimming, had been expected. The importance of novelty burn lines (patterns caused by watches, sandals, etc.) and the sensory experience of burn remedies (smell of Solarcaine, coolness of Noxzema, aloe vera) had not been predicted. The effect of pop culture, such as current fashion (wearing tube tops or flannel shirts) and the status of having a tan (able to travel for exotic holidays or just lie around outside), was another unexpected trigger. Thinking about best friends was a good trigger for anchoring time periods.

Most participants were confident that they could accurately recall their early years (age 6-11), and felt that the term “sun exposure” was a familiar one. There was general agreement that telephone interviews were unpopular and concern that the interview would be too long.

3.3. Design of Draft Instrument

In the key informant interviews and literature, there was general consensus that recall before age 5 or 6 was unreliable (Loftus 1993). We then observed that if we set our lower age limit to 6, we could take advantage of the structure placed on sun exposure by the school system. Between September and June, most children are outside for limited hours on weekdays between 10:00 am and 5:00 pm. This led to a natural separation between routines and activities during the school year and activities during the school summer va-

cation (July and August). The questionnaire was then divided into four “cycles”: School, School Summer Vacation, Work and Other. Each interview results in several School and School Summer Vacation booklets being completed. The Work cycle is intended for those periods when the respondent’s main activity was not school. The Other cycle is available for unexpected situations that require a more flexible reporting structure. Examples encountered to date include time off for travelling and home schooling.

A single calendar (“Biography”) records residence from birth to age 18, then school or employer, friends or caregiver, fall/winter/spring vacations, summer vacations and spring/summer/fall outdoor activities for ages 6 to 18. Early in the design process, it was recognized that one set of time periods (“chunks”), usually several grades spent in each school, could provide the basis for reporting activities with relatively homogeneous sun exposure during the school year. However, a very different approach was needed to handle the unstructured nature of school summer vacations and activities. A separate grid was designed for use by the interviewer to better identify activities that recurred over years and could have homogeneous exposure information. The grid also allowed the interviewer to more easily identify summer periods with missing data.

A background questionnaire about demographics and host factors was modified slightly to improve the responses to some questions (Marrett *et al.* 1992). The questions cover several risk factors for melanoma, such as skin/hair/eye colour and freckle patterns.

In order to help respondents use the triggers and cues identified by the focus groups, a single page with a list of outdoor activities was created, using the specific sports, chores and vacation pastimes they reported. As well, biographies were written for three fictitious respondents of various ages, to provide narrative examples of residences, schools, outdoor activities, summer jobs, vacations, etc.

Given the dynamic nature of the “chunking” of School and School Summer Vacation cycles, it became apparent that the use of a computer-assisted telephone interviewing system would be impractical. Experienced, highly trained interviewers would be required, for they would need to adjust quickly to the unique background and recall needs of each respondent. Knowing which cycles were necessary for each time period, and grouping activities to aid recall and reporting while maintaining rapport with the respondent, are

demanding tasks. Concern about the length of the interview (approximately one hour) and respondent burden remained.

3.4. Alpha Testing

In general, the results were encouraging and informative. The summer activity grid and the School Summer Vacation cycle needed work to make them more flexible and comprehensive, as well as making it easier for the interviewer to allow the respondent to recall their activities in the order they prefer. On the Biography and the summer activity grid, columns were included for year, age and grade, since each of these can help anchor activities in time.

Another important test of any questionnaire that should be done as early as possible is a check that required exposure measures could be computed from the data collected. Three of the alpha test interviews were crudely entered into SAS data sets, and it was verified that time in the sun can be calculated for single years of age. The data collected will allow examination of both amount and pattern (summer vs. fall/spring, weekday vs. weekend, vacations).

3.5. Cognitive Interviews

Overall, participants in the cognitive interviews appeared to use recall techniques such as visualization (imagery of places they've been, people they were with) and mentally walking themselves through situations and events. People reported that they often drew upon their experiences involving family members and family events to trigger their memories. These techniques helped them to answer the questions with greater confidence. At least two people guessed when answering questions about early life sun experiences, but these guesses appeared to be extrapolations from other situations, suggesting that events were lumped together to facilitate responding.

Since the measurement of early life sun exposure will rest on the use of specific terms such as sunburn, we paid close attention to how people thought about and defined these terms. While focus group participants generally reported a consistent definition for sunburn, some of the cognitive interview participants did not share this definition if it in-

cluded “blistering”. There was consensus between focus group respondents and cognitive interview respondents, however, that sunburn involves redness and pain. Therefore, if we had relied solely on the feedback from focus group participants to define sunburn in the final version of the questionnaire, we would likely have missed a significant proportion of sunburn experiences in the study population.

The cognitive interviews also demonstrated how specific time periods (during the day, particular months) are interpreted differently or are challenging to recall. For example, people in the cognitive interviews were generally less confident that they could accurately recall the time they spent in the sun after a school day than other times in their lives. Some people had also included March and November as winter months, or they described these periods as spring or fall. The school calendar year often acted as an important cue for memory, and as such, may have influenced how people think about these particular months. Nevertheless, this issue speaks again to the importance of establishing clear definitions for general terms that one might assume to be well understood.

We also learned that the term “recess” is not universal, and some cognitive interview participants had trouble distinguishing recess from lunch period. School experiences are so varied that particular attention needs to be paid to the language used to describe school-related events and activities.

The most challenging time for people to recall, not surprisingly, is the period under 10 years of age. Again, family members and family events were important cues, but participants did lump together their experiences to decide what they thought they would have been doing out in the sun during these early years.

Typically, instruments designed to measure sun exposure ask people about sunscreen behaviours. For older participants in the cognitive interviews, this was not a relevant question since sunscreens were rarely used during their childhood. Moreover, many of the participants reported (as they did in the focus groups) that any sun protective behaviours they practised in their earlier lives were dependent on parental intervention, particularly by mothers. Thus, they extrapolated their use of sun protective behaviors, such as sunscreens and clothing, on the basis of whether or not they perceived that their mothers had been aware of the damaging effects of the sun and translated this understanding into protective behaviours.

3.6. Formal Pretest

The formal pretest resulted in minor format changes to all cycles and more significant changes to the School Summer Vacation cycle.

While the school “chunks” seemed to evolve naturally around changes in residence or school, the summers did not necessarily follow this pattern. Respondents told us that it was difficult to average time outside across a whole summer because it often varied drastically from week to week (i.e., whether they were at the cottage, in summer school, hanging out around the house). We decided that rather than trying to impose the same time “chunks” used in the school cycle, we would “chunk” by activities. This allowed us to capture the usual exposure for the 8 years they went to a cottage, for instance, with just a few questions, as well as the one-time trip to Hawaii.

Only minor changes to the study procedures were made after the pretest. A postcard reminder is sent one week after the initial package, and phone follow-up begins after another week has passed.

3.7. Test/Retest with Cases and Controls

Recruitment and interviewing for the full study is currently underway. Monitoring of interviews and debriefing of interviewers will continue. The use of the phrase “weather permitting” was noted, alerting us to the mental adjusting some respondents are doing to adjust for rainy or cold weather. The recording of sun exposure length and frequency for the School Summer Vacation cycle continues to require refinement. The Work cycle is not flexible enough to cope with the irregular jobs often held by teenagers; the Other cycle is being reviewed to verify that it can be used instead. Currently, interviews are taking between 40 and 70 minutes.

4. Conclusions

Each step in our process yielded important information that influenced the development of the questionnaire. The key informant interviews reinforced the value of life event calendars. Focus group participants helped us understand how to cue people’s memories to achieve the highest possible accuracy in recall about these early years. By alpha testing

the new questionnaire on family members and co-workers, we were encouraged that our design would work and were able to quickly identify areas requiring more attention. The cognitive interviews took us beyond the focus groups, by clarifying terminology and providing context information in the questionnaire to stimulate recall. The formal pretest showed that study procedures were reasonable, while the continuing test/retest phase is informing us about the demands placed on interviewers and respondents.

Time and money are always limited, and few people have the resources to do all these steps when they are designing a questionnaire. We feel strongly that the multidisciplinary team approach is essential to bring together the skills required to address the complex issues involved in measuring exposure through the recall of early life activities. We also encourage the use of all these steps, even in a more limited fashion. Each step will help to ensure that the final instrument is measuring what it should, and that the data collected will be useful for understanding the role of early life behaviours.

The significance of our work goes beyond adult recall of early life sun exposure. Many of the issues around recall are the same for other routine exposures of early life, such as physical activity. It is likely that these methods will be effective in constructing instruments for the recall of other risk factors. We hope that our work will encourage other epidemiologists to consider their use when they design their questionnaires.

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