Title: The Lifecourse of Esophageal Cancer Patients Traced By Means of the Lifegrid

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Abstract:

Background:
The absence of prospective longitudinal studies for certain health outcomes creates the need to collect accurate information retrospectively. In an attempt to minimize recall bias and to better understand the deeper rooted issues involved in the risk factors for esophageal cancer, the adoption of the lifegrid accompanied by supplementary tools was implemented. The objective was to provide a more comprehensive and context-sensitive perspective to the study of the living and working environments of esophageal cancer patients across the lifecourse.

Methods:
A sample of 46 esophageal cancer patients were recruited from participating London and Toronto hospitals. This study involved the completion of face-to-face interviews guided by a semi-structured questionnaire, a lifegrid, occupational and residential summary boxes, residential pictures and occupational risk maps, and reference to other supplementary information and sources of evidence.

Findings:
The utilization of the life grid allowed for a holistic interpretation of the data allowing for a visual analysis of various factors at play across the lifecourse. The use of the lifegrid retained the temporal ordering of the lifecourse, made it easy to identify and probe for transitions and trajectories, and allowed for various links across factors to be made during data collection. Nevertheless, its use also produced a number of challenges such as lengthy interviews, event-centered data, and the inability to pinpoint specific unknown exposures. However, these limitations could be overcome by conducting multiple, short interviews, making modifications after pilot interviews, incorporating supplementary tools, and referencing sources of evidence.

Conclusions:
The lifegrid aids in stimulating recall in a factual fashion. The versatility of the lifegrid allows it to be easily modified based on different population groups and research objectives. With the integration of other supplementary tools, the adoption of the lifegrid is recommended as a methodological tool to guide other research pertaining to lifecourse studies.

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Keywords: esophageal cancer, lifegrid, living and working environments, lifecourse
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INTRODUCTION

Current research pertaining to the etiology of esophageal cancer often adopts conventional epidemiological methods which tend to focus on a limited number of possible risk factors and thereby addresses a specific period in a person’s life. This approach leaves several gaps in knowledge about the inter-related causes of esophageal cancer and the context in which they occur. The absence of prospective longitudinal studies for less common forms of cancer such as esophageal cancer, creates the need to collect accurate information retrospectively. In an attempt to minimize recall bias and to better understand the deeper rooted issues involved in the risk factors for esophageal cancer, the adoption of the Lifegrid accompanied by supplementary tools was implemented.

The objectives of this study were to:

i) Provide a more comprehensive and context-sensitive perspective to the study of the living and working environments of esophageal cancer patients across their lifetime.

ii) Assess the utility of the Lifegrid.

iii) Implement a more holistic approach to the study of esophageal cancer.

METHODS

The research design retained esophageal cancer patient’s lives starting from birth to present day and included detailed questions pertaining to the last thirty years prior to diagnosis to account for latency.

Esophageal cancer patients who spoke English and were over 18 years of age which were seen in thoracic clinics at St. Joseph’s Health Centre (Toronto) and the London Health Sciences Centre between January 2008 and November 2008 were approached for inclusion in the study. Patients who were cognitively impaired or too ill to participate were excluded.

The interviews took place at a time and location convenient for the patient. All interviews were tape recorded to ensure accuracy. The average interview lasted 4:18:17 in length (Mean: 3:57:46; Max: 4:18:59).

Sources of Data

Life story interviews included the use of:

- A Lifegrid
- Reference to other supplementary information at the time of the interview to assist in obtaining accurate information
- A semi-structured interview guide/guiding survey tool
- Occupational and residential summary sheets
- Occupational risk maps and residential pictures as necessary
- Reference to pathology reports to confirm diagnosis
- Personal reflections and field note observations

Data Analysis

A password-protected SPSS database was created to run frequencies and cross tabulations on demographical variables, as well as analysis on etiological and other factors that were explicitly examined and which emerged during data collection and Lifegrid analysis.

Holistic content analysis was employed as the primary method for analysis of the narratives.

Demographic Profile of Sample

<table>
<thead>
<tr>
<th>Variable Category</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>Male 75%, Female 25%</td>
</tr>
<tr>
<td>Age of Diagnosis</td>
<td>Mean 66, SD 11.94 years</td>
</tr>
<tr>
<td>Employment Status</td>
<td>Employed 14%, Unemployed 86%</td>
</tr>
<tr>
<td>Highest Level of Education Attained</td>
<td>No School Degree 9.1%, Grade 9 or Less 32.7%, Secondary or More 58.2%</td>
</tr>
<tr>
<td>Married at Time of Diagnosis</td>
<td>Married or Common Law 62.5%, Single 36.9%, Divorced or Separated 0.6%</td>
</tr>
<tr>
<td>Country of Origin</td>
<td>North America 8.2%, United Kingdom 19.3%, Europe 19.6%</td>
</tr>
</tbody>
</table>