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/or only 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 lifecourse.

ii) Assess the utility of the lifegrid.

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

METHODS

❖The research design retraced 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 4:10:17 in length (Min: 1:57:46; Max: 10:06:58).

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 boxes
❖occupational risk maps and residential pictures as necessary
❖reference to pathology reports to confirm diagnosis
❖personal reflections and field note observations

Data Analysis

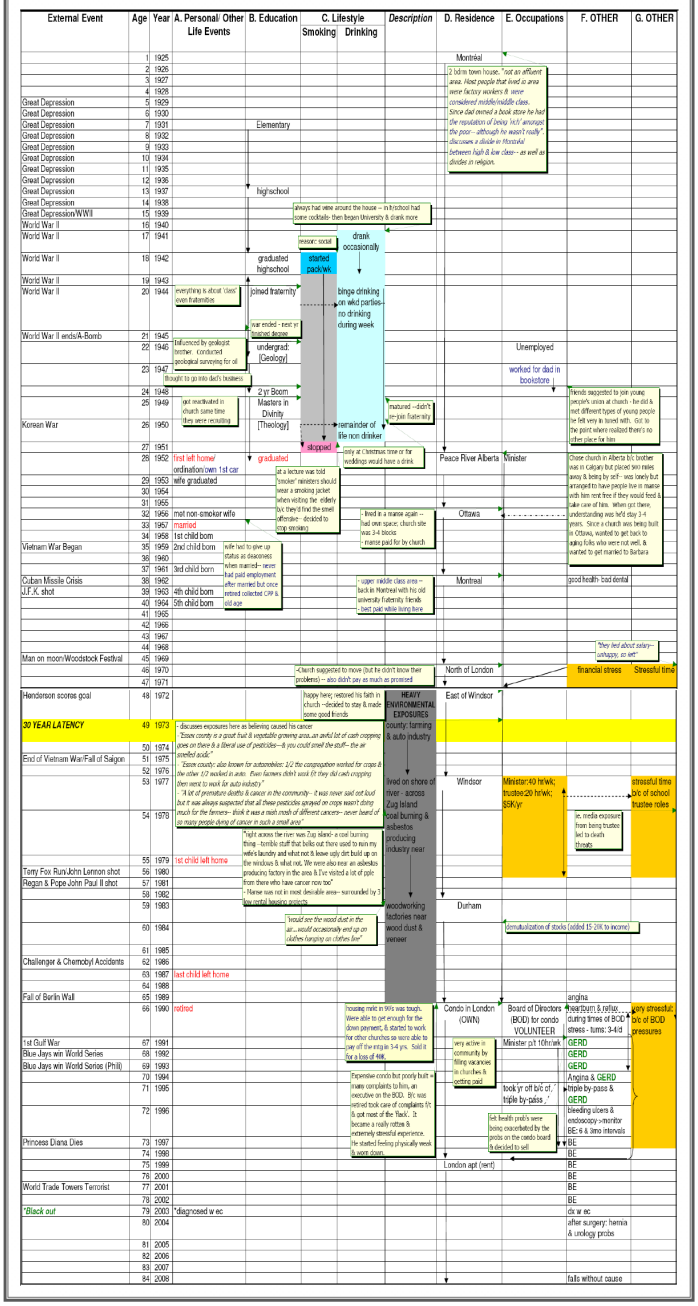
❖A password-protected SPSS database was created to run frequencies and cross tabulations on demographical variables, as well as analysis on etiological and other factors that were explicitly examined and which emerged during data collection and lifegrid analysis.

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

Demographic Profile of Sample

Profile Categories	Findings
Sex	13 women and 33 men (n = 46)
# of Months Post Diagnosis	Mean: 25 Min: 2 Max: 106 Standard Deviation: 26 months
Age at Interview	Mean: 66 Min: 34 Max: 83 Standard Deviation: 11.4 years
Employment Status	Employed: 17.4% Retired: 54.3% Too Sick to Return to Work: 28.3%
Highest Level of Education Attained	Secondary or Less: 63% Post-Secondary or Higher: 37%
Marital Status at Time of Diagnosis	Married or Common Law: 65.2% Single: 6.5% Divorced or Separated: 15.2% Widowed: 13%
Country of Origin	North America: 65.2% Scandinavia: 2.2% United Kingdom: 15.2% Europe: 17.4%

Sample Lifegrid



RESULTS

The lifegrid as a data collection tool

❖Has been tested for accuracy against the Boyd Orr and Mass Observation Archive
*Has not been tested against other interview methods – however a tool very similar to the lifegrid was and it received positive results

❖Various recall strategies and timely probes can be used to enhance data quantity and quality
*Use of recall strategies as well as a complex lifecourse increases the timing of the interviews, could lead to meaningless tangents, and its detail-oriented nature requires large amounts of cognitive effort

*Data collected risks being event centered if proper probes are not utilized throughout and questions which invite extended accounts and elaboration are not incorporated

*Not enough or too much information may result in ineffective recall strategies

❖Minimizes telescoping errors and has the ability to identify and fill gaps in the lifecourse
*Historical truths may not always be represented unless compared against other sources of evidence

❖Builds rapport, allows for a level of comfort and familiarity with the participant, and creates a sense of control and direction
*Participants may inadvertently disclose information not intended

❖Versatile in structure and research use

❖Allows for visual representation

The lifegrid as an analytical tool

❖Allows for an easy visual of reoccurring themes and connections between variables both during data collection and analysis
*Bias may inadvertently occur

❖Provides a holistic picture and allows for data transparency

❖Retains timing, sequence, and context

CONCLUSIONS

❖The use of the lifegrid has shown to have dual methodological capabilities; both as a data collection tool and for analysis.

❖The lifegrid as a data collection tool aids in stimulating recall in a factual fashion.

❖With the integration of supplementary questions, patient stories are brought to life through memory recall which is anchored by events and other details significant to the story-teller.

❖When possible, reference to supplementary data is recommended in order to ensure accuracy of environmental and occupational exposures and to ensure historical truths are being reflected.

❖ The lifegrid as an analytical tool allowed for data transparency and provided a holistic and context-sensitive perspective to the study of the living and working environments of esophageal cancer patients across their lifecourse.

❖The lifegrid is recommended for use as a supplementary tool to both guide and act as a form of analysis for similar research pertaining to the field of lifecourse studies.

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