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Development of a Method to Obtain More Accurate General and Oral Health Related Information Retrospectively

Golkari A[a,b]*, Sabokseir A[a], Blane D[c], Sheiham A[b], Watt RG[b]

[a]Oral and Dental Disease Research Center and Department of Dental Public Health, School of Dentistry, Shiraz University of Medical Sciences, Shiraz, Iran
[b]Research Department of Epidemiology and Public Health, University College London, London, UK
[c]Department of Social Science and Medicine, Imperial College London, London, UK

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Corresponding Author:
Ali Golkari
Department of Dental Public Health, School of Dentistry, Shiraz University of Medical Sciences, Shiraz, Iran
E-mail: golkaria@sums.ac.ir, aligolkari@yahoo.com
Tel: +98-711-6263193
Fax: +98-711-6270325

Abstract

***Statement of Problem*:** Early childhood is a crucial period of life as it affects one's future health. However, precise data on adverse events during this period is usually hard to access or collect, especially in developing countries.

***Objectives*:** This paper first reviews the existing methods for retrospective data collection in health and social sciences, and then introduces a new method/tool for obtaining more accurate general and oral health related information from early childhood retrospectively.

***Materials and Methods*:** The Early Childhood Events Life-Grid (ECEL) was developed to collect information on the type and time of health-related adverse events during the early years of life, by questioning the parents. The validity of ECEL and the accuracy of information obtained by this method were assessed in a pilot study and in a main study of 30 parents of 8 to 11 year old children from Shiraz (Iran). Responses obtained from parents using the final ECEL were compared with the recorded health insurance documents.

***Results*:** There was an almost perfect agreement between the health insurance and ECEL data sets (Kappa value=0.95 and $p < 0.001$). Interviewees remembered the important events more accurately (100% exact timing match in case of hospitalization).

Conclusions: The Early Childhood Events Life-Grid method proved to be highly accurate when compared with recorded medical documents.

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Introduction

Life course epidemiology is a multidisciplinary approach to the study of health, its components, and its compromising factors. It attempts to integrate short- and long-term effects of different kinds of physical and psychological factors that affect the development of diseases, and to study them longitudinally throughout the course of life of individuals, instead of looking at specific cross-sectional points of life [1]. The factors assessed include past health status, genetic differences, behaviours, and environmental

exposures that may directly or indirectly affect the health of individuals or populations, starting from their gestational life or even previous generations [2]. Although life course epidemiology assembles a considerable amount of early childhood related data from cohort studies, especially birth cohorts, link registered methods and clinical assessments, the retrospective questionnaires remain vital for such studies [3]. Unfortunately, little research has been conducted to develop methods to collect accurate data from early life for life course studies.

Data Sources/ Data Collection for Use in Life Course Epidemiology

There are four main sources of life course data: cohort studies, linked-register method of collecting data, clinical assessments, and retrospective questionnaires. These methods are briefly reviewed here.

Birth cohort studies have been the main sources of data for life course epidemiologists, especially those with an interest in the role of early childhood. However, cohorts have their own disadvantages. That makes it impractical to exclusively rely on them. One disadvantage is that they are mainly done in more affluent countries because of their cost. Another problem is the long time needed to yield results [4]. For those reasons, the number of birth cohorts from which data can be used to assess influences of early childhood on later age is limited to those started in mid-20th century in northern countries and, therefore, cannot be extrapolated to less affluent countries. Cohorts are also vulnerable to the new questions that arise by advances in understanding of health components and risks [4].

Cohort studies, similar to other longitudinal studies, are affected by sample attrition over time. That is more common in birth cohorts where subjects frequently move from their residence. Last but not least is that although cohort studies are meant to be conducted as a contemporaneous observation, they are usually framed by several retrospective questionnaires asking subjects about events that occurred during short periods of their past, usually the period between the two questionnaires/interviews. This depends on remembering events of the past few months or years by them. Due to the disadvantages mentioned above, although the best type of life course epidemiology is still considered to be a cohort study from birth, many researchers have to use fully or partly retrospectively collected data.

Since the 1990s, linked-register methodologies have been used in a number of life course studies to assure the reliability of information obtained from the past. In this method, past life information obtained by a questionnaire is compared with documents kept by households, registered information from hospitals or clinics, and data gathered by other researchers [3]. This method is mainly used to obtain data from birth, as the most accessible registered data [5] and gestational life, as these are not included in most cohort studies [6,7]. Although most of the data obtained by this method are highly reliable, their application is limited by the limited amount of information that is recorded.

Clinical assessments such as clinical examination, anthropometric measurements, body activity tests, and most importantly, laboratory tests can also be used to obtain some data on the present and past health status and possible exposures to risk factors. The main disadvantage of these assessments is that they are restricted to physical measures. Non-organic past exposures cannot be readily assessed with this method. Moreover, this method would not provide much information, even on the past physical exposures, because they are masked by the affected tissues or healing of organs.

Retrospective questionnaires, although of questionable accuracy, is the only data collection option left to many epidemiologists. Nevertheless, it is vital to have a good questionnaire combined with a good method of interview to help people remember past events, especially to remember the precise timing of events. Designing such questionnaires so that an acceptable degree of accuracy is achieved, or development of methods to validate the previously obtained data, remains a challenge for many researchers.

Retrospective Data Collection

Retrospective data are mainly collected using either self-administered or interview-based questionnaires and by asking the subjects about themselves or their relatives' past experiences. Questionnaires rely on respondents answering questions correctly. Several factors may compromise the quality of the data obtained. However, the most important factors to improve the accuracy of data are: 1) convincing the respondents to participate and answer fully and honestly, and 2) to trigger their memory to remember events and their precise timings. The former is a matter of sample recruitment, design of questionnaire and attracting the subjects' interest and trust. These are usually tested and reported, for example, as the response rate and missing values or by comparing responses to parallel questions. The latter, however, has always been problematic, especially because it is difficult to measure the accuracy of people's memory.

The usual way to test the accuracy of the subject's answers is to compare them with the existing recorded documents. However, such documents covering the life course of subjects do not usually exist. If they do, there is no need to collect new data retrospectively. Even if such reports exist, no recorded document is perfectly accurate. Therefore, unknown level of accuracy of data can be considered as the main shortcoming applicable to many life course publications [3]. This is a further reason for developing better methods to improve the accuracy of people's recall and practical ways to validate them.

Several intuitive ways have been introduced (usually by psychologists) that claim to help people to remember their past events more accurately [8]. One method with the most promise is the life-grid method [4]. It has proved to make significant differences in reliability and accuracy of recalls, especially when precise time or age of events matters [9,10].

Life-grid method of collecting past life course data

Individuals differ in their capacity to remember. This is particularly true for autobiographical "extended special events" and "life time period" memories [11] which are the usual targets of life course epidemiology questionnaires. However, there are certain outstanding events that people remember better. Such events are personal landmarks such as birth, marriage, birth of children, death of close relatives, or important educational steps. Others are public landmarks that had impacts on the person's life. They include wars, natural disasters, and major political changes [4,12].

These outstanding events or "landmarks" can be used to improve the memory of other less important personal events. Even if the exact timings of some events are not remembered by respondents, they might still be able to recall the order of events by linking them to landmarks if each target event happened soon after or before a landmark event. Two or several landmark events with known timings can be used to help the subjects remember events that happened between landmarks, or to recall timing of an event. A method called bounded recall [12,13] was used to develop a technique called Event History Calendar (EHC). In EHC, the timings of a series of landmarks, either personal or public, are first discussed with the interviewee. Subjects will be prompted by the interviewer, first to trigger their memory and later to anchor their memory and place events with unknown timings in the time period between two landmarks [14].

The EHC was further developed into a well-designed life-grid method of collecting retrospective data. In the original method, introduced by Blane [4], the questionnaire is accompanied with a grid-like table with four major columns; the first 4 columns of the current study's early childhood events life-grid. The first column is called external line and contains time and important events outside the family known as public landmark events. All subjects or at least those who live in one area share the external line. The second column is called personal lifeline. Information regarding important events inside the family, such as births, deaths, marriages and divorces, are put in this column. The third column called residential line, contains data about type, size, facilities and addresses of all houses that the target person has lived in. The last column is occupational line and is about changes in a person's work status and certain conditions of jobs. The information related to each column is gathered and checked in relation to other columns and corrections made as the interviewee remembers more details.

Studies by Blane showed that people were happy with the method as they remembered precise details of their life with this method and reported reasonable proportions of precise data collection when results of the life-grid were compared with documents. The proportion dramatically increased from 41% -100% to 83% - 100%, when small mistakes were ignored [4, 10].

There is a controversy about letting the respondent see the grid while it is getting completed, as that will help the process of remembering events. Showing people the results of their pervious answers may give them more ideas about the events related to them, but at the same time it omits the triggering effects of an event being prompted by the interviewer. Moreover, the way the life-grid was used in recent studies looks complicated and might cause confusion or loss of orientation. On the other hand, having some illustrative material may be a simple timeline showing two ends of the period of time being discussed in the interview and locating events between them. That has proved to significantly increase the accuracy of answers [8,15,16]. A semi-structured method of questioning, which includes free recalls inside each column, also improves the quality of data obtained by giving time for the respondent to think and choose from those events that they remember first [16,17].

Since its introduction, the life-grid method has been extensively used worldwide and has shown to be very good at obtaining accurate timing of the past events in both qualitative and quantitative studies [8-10,16,18-22]. In most of these studies the life-grids were slightly changed and adapted to gain desirable

information based on the objectives of each study.

Despite the extensive use of the life-grid and the event history calendar (EHC) methods by epidemiologists during the last decade, only two studies have used a rigorous approach to test the concurrent validity of these methods by comparing their findings with the recorded documents or previously collected data. Berney [10] compared the family and household data of 26 subjects obtained by the life-grid method after 50 years with recorded documents when exact timing of events was not one of objectives. He reported a kappa value between 0.41 and 1.0 for the agreement between the two data sets. The levels of agreement increased markedly when "$\pm$ unit" was added to the exact matches ($0.83 < k < 1.0$)[10].

Belli *et al*. [23] interviewed more than 600 randomly selected subjects on social and economic events occurring in the past 2-3 years by either the conventional question-list method or an event history calendar (EHC) method. They compared the results of both groups with the previously collected data as "gold standards". The agreement between data collected by EHC with the gold standards was substantial for 7 categorical variables ($0.63 < k < 0.79$) and significantly higher than the conventional method for 2 of them. They also found significantly higher correlations between the EHC method and gold standard than the conventional method for 6 out of 9 continuous variables. Again timing of events was not an objective [23].

All published papers using the life-grid or EHC methods have reported high levels of satisfaction and accuracy either tested by qualitative methods or based on the researchers' experience. The method has been used as the best available method in collecting the past life course data in two well-known studies, the national English Longitudinal Study of Aging (ELSA, 2008) and an international Survey of Health, Aging and Retirement in Europe (SHARE) [8,24]. Computerised versions of the life grid method were used in SHARE study. Through computer based grids, a wide range of information on landmarks is provided for both interviewee and interviewer and, therefore, more accurate data are collected in relatively short interviews [8].

Shortcomings in Methods for Early Childhood Data Collection and Validation

The significance of the early years of childhood is the frequency and variation of important developmental milestones and occurrence of affective life events [25]. As subjects would not have much idea about these events, parents/caregivers should be asked about them. However, there is a tendency for parents to remember dates, duration, and severity of only a few adverse events in their children's early life, especially when they occur close to each other. Parents may not be aware of children's important life events if the child had other caregivers, or parent may mix up the events that occurred to their children if they had two or more children born shortly after each other. In addition to the unreliable memory of parents, partially and inaccurately recorded medical and dental documents, if any, make it difficult to assess the health-related risk factors occurring in this crucial period of life [26].

Despite the emphasis on the outcomes of the early childhood events, life course epidemiology has made few efforts to develop methods to collect accurate data from early life. Looking at the broad span of life, most life course approaches use long periods of time, years and decades, as their index. So, even when the early childhood events are considered in their data collection, several events occur in one period, and are, therefore, not accurately recorded.

The life-grid and the event history calendar methods were originally developed for adults, especially the aging groups. Childhood data collected in some studies using these methods, whilst being the best method used in life course retrospective data collection, are too inaccurate [4,21,27]. This led the authors to consider developing better life-grid methods for accurate collection of early childhood data. The best method would be a special life-grid designed for early childhood containing developmental milestones and shorter periods of time for the earlier years, filled in by questioning parents or caregivers. The objectives of the current study were to develop a life-grid method to collect data on events in early childhood and test its content and concurrent validity.

Materials and Methods

A life-grid was developed to collect data on events in early childhood events. Ethical permission to collect data based on the development of a life-grid was obtained from Shiraz University of Medical Sciences. The life-grid was used with a simple life line from birth to the present age of the child. Relevant questions entered into each grid. A pilot study was conducted on 12 children followed by a main one on 30 children aged 8-11 years of age. Their parents were contacted and interviewed after explaining the objective. Content validity and relevance of the columns of the

life-grid was assessed in the pilot study. Accuracy and concurrent validity of the life-grid was tested in the main study.

The Early Childhood Events Life-grid

The early childhood events life-grid is a table with 22 rows and 11 columns (Table 1). The first row is for headings. The other 21 rows contain age periods from "immediately after birth" to "7-8 years" and events happening during them. The first age periods are shorter as they are more important in physical and mental development and contain more changes in the

Table 1: The early childhood events life-grid

Age(and External line)	Personal life line	Residential status	Occupational line	Child activity line	Height	Weight	Illnesses	Medication	Hospitalization	Accidents/falls
Immediately after birth										
Up to 1 month										
months 1-2										
months 2-3										
months 3-4										
months 4-5										
months 5-6										
months 6-9										
months 9-12										
months 12-15										
months 15-18										
months 18-21										
months 21-24										
years 2-2.5										
years 2.5-3										
years 3-3.5										
years 3.5-4										
years 4-5										
years 5-6										
years 6-7										
years 7-8										

child's life and activity.

The first column is the external life line and contains age periods and codes of some national and local events which are easy to remember and easy to relate to the past life. The second column is personal life line. Events such as birth of younger brother(s) and sister(s), death of a close relative, divorce and new marriage of parents and the time at which older brother(s) or sister(s) went to school/nursery are recorded in this column. The third column is for information regarding residential status of the family. Changes of address, changes to the shape or plan of the house, and owning a car, landline telephone or mobile phone numbers would be written in this column based on questions on Card 2. The fourth column of the life-grid belongs to the occupational status of parents/caregivers. This information is obtained based on questions on Card 3. The fifth column records the child's activities including infant feeding practices. Questions regarding the child's activities are shown in Card 4. Columns 6 and 7 show the height and weight of the child obtained from the child's growth chart and inserted into appropriate cells. Columns 8 to 11 were marked by codes based on questions about illnesses, medicine used, hospitalization, and accidents and falls in Card 5.

Life Line

As the life-grid was rather complicated, a simple line was shown to parents during the interview. The line started with the child's birth and ended at the current time. While the questions are answered by the parents, each event is marked on the line based on the approximate time given. As the interview proceeds, more events are marked and some previous markings are corrected based on the new answers.

Cards as illustrative materials

Five cards were used:

- Card 1-4: Contain questions relating to the second to fifth columns of the life-grid (personal life line, residential status, occupation of parents/guardians, and child activity line).
- Card 5: Contains questions on illnesses, medication and hospitalization and a list of important diseases.

Calibration of Interviewers

The main examiner (AG) was trained and calibrated to conduct life-grid interviews by two international experts in this method and gained experience of doing so by interviewing several parents of school-aged children. The main examiner (AG) then acted as the "gold standard" interviewer to train and calibrate the 4 others, all being professional health workers. At the end of the calibration process, one person (ASa) was chosen based on having the highest intra-examiner reproducibility and highest inter-examiner agreement with the gold standard examiner.

Explaining the Study and Gaining Consent

Upon arrival at the clinic and before conducting any investigation, the purpose and stages of the study were explained to the parents in detail and their consent was requested. Ethical permissions were shown with the request, and the researchers' contact details were recorded in case they were interested in the results of the study.

Interview

Each interview with parents/caregivers was conducted by two of the three calibrated interviewers. First, personal data were double checked with the interviewee. Then, questions regarding the child's birth conditions were asked. In the next step, the interviewees were asked questions regarding family life, residential status, and occupation of the parents/caregivers, child's activities, illnesses, medication, hospitalization, accidents and falls in a life-grid method and based on cards 1 to 5.

As the interviewee did not need to read the questionnaire, it was not translated into Farsi. However, two tools were used to facilitate the interview: 1) a list was shown to the interviewee to remind him/her of some important and common childhood diseases, and 2) a single line showing the child's birth and present age at the two ends was used. Each event remembered by the interviewee was marked on the line in relation with other events to obtain the correct time and order of the events.

It was possible to enter each life event as a code in the appropriate cell of the life-grid. However, in practice it was confusing for the interviewers and could increase the possibility of making mistakes. Thus, it was decided to write the name of each illness, as mentioned by the parent, into the appropriate cell. Medication, if used, was marked in its own columns of the life-grid. If the child had been hospitalized, that was marked in the appropriate cell. For boys, circumcision status and the date it was done was one of the questions.

Height and weight of the child from birth to the current date was entered from the child's growth chart into the respective column of the life-grid. The whole interview was tape recorded for further investigations by using a digital voice recorder if the interviewee

agreed.

The pilot study

A convenient sample of twelve 8 to 10-year-old children was selected from the patients attending a clinic in Shiraz. They were usually accompanied by their mother or grandmother. The Relevance of Columns in the Life-grid was tested in two ways. First, the impact of the questions/answers of each column on the correctness of the answers given was observed. Then, after each interview, the interviewee's opinion was obtained about the importance of each category of questions (columns), helping them to remember the past events.

Main study

A multi-stage random sample of 110 children aged between 8 to 11 years was chosen from primary schools of Shiraz city. Their parents were asked to bring the children's health documents, such as birth card, growth charts, immunization card, and medical insurance records, to the interview. Parents were entered into the study only if 1) the documents covered their child's whole life and were fully filled in, 2) the parent/caregiver was in charge of caring for the child from birth to the present time, and 3) they gave consent for interview and access to the child's health documents.

The exact age of the occurrence of any change of address, any hospitalization, any accidents/falls, and those illnesses reported by the interviewee were extracted from the health documents. This information was assumed as "gold standard". Validity of the life-grid was assessed against this gold standard by using Kappa agreement coefficient. SPSS statistical software version 18.0 (SPSS Inc., Chicago, IL, USA) was used for statistical analysis.

Results

The average time for interviews was 50-60 minutes. The life-grid collected all desired factors that were considered when designing the life-grid such as strong psychological events, change of address, feeding pattern, and milestones in child activities, viral and non-viral illnesses, medication, hospitalization, falls and accidents.

All 12 interviewees participating in the pilot study agreed that the life-grid method was very useful to help them remember events and to correct the times of events. Most columns of the life-grid had a great impact on the correction of timing recorded in the other columns (Table 2). The child's activity line had the greatest impact on the correction of the other columns. Different child's activities also helped the interviewees to correct the timing of other activities in the same column. The external line had the least impact. During the pilot study, it was shown that the number of older and younger brothers and sisters, and also the mother's age at the time of the child's birth were important information to be asked about and recorded.

Table 2: Number of cases that each column of the life-grid helped to correct the timing of events in other columns (N = 12).

Column	External Line	Personal life line	Residential status	Occupational line	Child activity line	Illnesses	Hospital-ization	Accidents /falls
Number of cases that corrected other columns events by using this column	0	2	5	3	10	3	3	1

Among the 110 parents who were asked to bring their children's health documents, 94 replied. Only 30 had the desired criteria to be included in the study. Fifty five of them did not have all the documents we needed. Three parents indicated that their children were raised by their grandparents up to a specific period and, therefore, they were unaware of some of their children's early childhood events. And six more did not want to participate in the study after the aim and process of the interview was explained to them. There was no significant difference in age (p-value = 0.723), sex (p-value = 0.899), or area of living (p-value = 0.095) between parents who included and those who were excluded from the study.

Table 3 shows the agreement between the findings of the life-grid and recorded events in the health documents (the gold standard) in relation to the four main variables. All events reported by the life-grid were found in the health records. Less exact matches were found for less important health related events such as change of address, and more exact matches were found for the more important ones, such as hospitalization. The Kappa agreement value was 0.95 when only exact time matches were assumed as agreement.

In the next step, if an event reported by the parents was in the adjacent grid to that found in the health document (just one grid difference between the time reported in ECEL and found in the documents), it was

Table 3: Agreements and disagreements between the findings of the life-grid method and the recorded health documents (N=30).

Event	Exact time Match	One grid Disagreement	Two or more grids dis-agreement	Not reported in life-grid but recorded in health documents	Total	Agreement level (k) of exact matches
Change of address	32(82.1%)	1(2.5%)	0(0%)	6(15.4%)	39(100%)	0.90
Illness	68(95.8%)	3(4.2%)	0(0%)	-	71(100%)	0.98
Accidents/falls	17(89.5%)	0(0%)	0(0%)	2(10.5%)	19(100%)	0.94
Hospitalization	12(100%)	0(0%)	0(0%)	0(0%)	12(100%)	1.0
Total	129(91.5%)	4(2.8%)	0(0%)	8(5.7%)	141(100%)	0.95

assumed to be an agreement. In that way, the Kappa agreement was increased to 0.97. These values show that there was an almost perfect agreement between the life-grid and the data recorded in health documents [28], and thereby high concurrent validity was found for the ECEL method. The agreement level between the two data sets for each variable is shown in Table 3.

Discussion

The life-grid method collected the past childhood life events accurately in terms of the number, nature, and exact timing of events. The agreement level (k = 0.95) between the findings of the life-grid method and recorded health documents was almost perfect. Less than 10 percent of events recorded in the health documents were not reported by the respondents or were reported a few months sooner or later than the time recorded in documents. There was no event that was only reported by the life-grid and not in the records.

In cases of disagreement, there was no way to find out which one was correct as the health record may have been wrong. It was a usual practice for Iranian doctors not to fully complete the health forms [29]. However, it was very unlikely that any agreement between the life-grid and health documents was wrong or achieved by chance [10]. A false agreement needs the respondent to give an inaccurate answer that exactly matches the wrong answer recorded in the health documents. Neither the respondent nor the interviewee was aware of any accidental mistake in the health document.

Accuracy of data obtained by the ECEL ($0.90 < k < 1.0$) was significantly ($p < 0.001$) higher than those of the only comparable studies which reported $0.41< k < 1.0$ (10) or $0.63 < k < 0.79$ [23]. Of course, the difference between the results of this study and those of Barney and Blane [10] was not significant after + one unit and + one grid were added to exact matches. This was due to the limited space for improvement in Kappa values related to the early childhood events life-grid, as it was already very high, compared to the other study.

Both interviewers and parents considered that the life histories of children were well displayed on paper as evidenced by the friendly interaction between interviewers and respondents. The method of prompting by the interviewer using previous answers triggered the respondent's memory. A short silence showed that they were thinking again, and then a correct answer was given with more confidence.

Participation in the interview, despite being a long procedure, was pleasant and encouraging for the respondents. Even the least interested respondents, who started the interview with doubts about the study, were, by the end of the session, excitedly participating in correcting the answers. The process of interview with a life-grid with several lines and words looks at the first glance to be a hard task for interviewers. In practice, however, the interviewers found the whole process easy.

The external line had the least impact, as interviewees mostly could not relate the events of this line with those of other lines. This was consistent with the findings of [30], indicating that the respondents were not able to correlate the external landmarks as well as personal landmarks to their life events. The value of this line is also consistent with the other studies in which crucial external events (like a war

or an earthquake) were used in broader time periods such as years or decades [10,16]. The SHARELIFE project, a European study collecting data on past life events of people aged 50 or more, tested a solution to this problem. Their interviews are computer-based. A long list of important public events is preprogrammed. The respondents had the chance to choose the events that they remember better and the computer finds the exact date of them [8]. This method is used in Europe and might be difficult to employ in developing countries, where a computer might not be available in all interviews, or interviewees might be familiar with such computer aided and rather complicated process.

A limitation of this study was the unavailability of health documents that forced the researchers to exclude about half of the the invited samples. The response rate (27%) was low for that reason. Of course, this low rate cannot undermine the fact that the ECEL methods showed high content and concurrent validity, especially because there was no significant demographic difference between the included and excluded samples. The poor state of record keeping in Iran [29,31] was another important issue. Less than half of the invited children had relatively complete medical insurance records. In some cases, parents had thrown their older records away. The possibility of accidental or intended 'mistakes' in health documents forced the author not to include "illnesses recorded in documents but not reported in the life-grid" in the life-grid method's validation study. For the same reason, it was not possible to say which one, the record or the life-grid, was correct in the case of disagreement between them.

Conclusions

The Early Childhood Events Life-Grid method proved to be highly accurate when compared with recorded medical documents. However, the accuracy can be further improved if any available recorded document is first accessed. The findings from such documents can be used by interviewers as landmarks; solid events with known dates. Further work may reveal how external line (public events) can be used in early childhood events life-grid. Furthermore, the method's reliability needs to be tested.

Conflict of Interest: None declared.

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