

The Lifegrid Method of Collecting Retrospective Information from People at Older Ages

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Abstract

An increasing proportion of the UK population is now aged over 60 years. Health services research involving elderly subjects is likely to become more common; and there will be a need for research methods that are adapted to this age group. The lifegrid is one such method. It has been shown to enhance long-term recall, is sensitive to the circumstances of individual subjects and modifiable to meet the research needs of different studies. The present paper details the development of the method and shows how it was informed by findings from a variety of academic disciplines. Use of the lifegrid method is illustrated step by step and its application in several studies described. The paper ends with suggested guidelines for using the lifegrid method when researching people with dementia.

Introduction

With an growing proportion of the UK population now aged 60 years and over, there will be an increased need for social science research on the problems faced by this group. Some of this research will require life course data. It will be necessary for researchers to modify existing tools and develop new methods to address the unique challenges of research in this area. Birth cohort studies, which hold prospective life course information, are of crucial importance. It has been noted elsewhere (Blane, 1996; Berney and Blane, 1997) however, that there will remain a need for retrospective data. Such data are complementary to the ongoing birth cohort studies and address some of the problems that such studies face. These problems include sample attrition, whereby members of the original cohort are lost to follow-up; the emergence of new research questions and the need to obtain different data from that which was collected when the study began; and the often immense cost, both in terms of money and time, that cohort studies can involve.

Key to the process of collecting retrospective data is the need to reduce recall bias. Whilst it may be impossible to completely eliminate such bias, particularly when the periods of recall span several decades, there is nonetheless scope for improving interview techniques in such a way as to minimise the effects of bias. This paper is not specifically concerned with people with dementia. Rather, it focuses on the practicalities of using the lifegrid method and the rationale behind its development. However, issues of memory loss and the appropriateness of the method for use with people with dementia will be discussed.

Which Items are Recalled with what Degree of Accuracy?

The fields of epidemiology, psychology and oral history have much to inform the social science researcher. In the first instance, epidemiological studies which have examined precursors to ill health in later life provide a wealth of objective data on the ability of subjects to remember such things as height, weight, smoking status and diet. Several studies (Must et al, 2002; Walton et al, 2000; Casey et al, 1991; Dwyer et al, 1989; Krall et al, 1989) have followed cohorts of volunteers over periods of up to 50 years. Baseline data taken at the commencement of these studies was then compared with the subjects' recall of these data as measured during the follow-up examinations. Wide variations have been reported in the levels of recall accuracy and not all types of information are retained to the same degree. Recall of simple occupational and residential data has been shown in numerous studies to be relatively accurate. Even after a number of decades, over 80% agreement between subjects' recall and official records and archived data has been reported (Auriat, 1992; Baumgarten et al, 1983).

Indeed, it appears that some items of biographical data can be recalled with useful degrees of accuracy after periods of over 50 years (Berney and Blane, 1997). Future research can draw on these studies to determine what items of information one can reasonably expect subjects to recall. Studies should also be aware of the items that are particularly prone to recall bias, and what items are liable to be biased according to the sex or age of the respondent. Accuracy of recall of food consumption has been shown to be relatively poor (Dwyer et al, 1989). This may be due to the sheer number of different items that can make up an

individual's diet. It may also be the case that diet, along with other recalled items, carry with them a certain significance that makes them more prone to recall bias. Social science research can place such items into a context where we can offer explanations for some of the bias. For example, the changing status of cigarette smoking over the last 30 years, from a being widespread practice to one that has become the subject of numerous official prohibitions (e.g. the banning of smoking in public buildings and areas at the workplace), has the potential to lead to subjects misreporting their past or current levels of smoking (Kesmodel and Olsen, 1999; Shiffman et al, 1997). A similar effect may also be observed with exercise. Given the increasingly elevated moral status ascribed to exercise in recent years, over-reporting of physical activity may also be observed (Matt et al, 1999). In seeking to minimise recall bias therefore, it is an important consideration for researchers that the information they seek to obtain from subjects be as 'morally neutral' as possible. Where this is not possible, researchers must acknowledge the above listed factors as possible sources of bias and treat their data with appropriate caution.

Aiding Recall

Different types of recalled data can be of relevance to contemporary health-related studies. Recall of past diet can provide information of use to studies looking at risk of hypertension or coronary heart disease in later life. Similarly, recall of past levels of smoking or exposure to fumes and dusts in the workplace may be of use in studies on chronic obstructive airways disease and lung cancer.

Oral historians have found that the order in which one asks questions can have a bearing on the subject's recall. Where one is interested in the date of an event, it may help to place that event in a wider context before pressing for exact times. Thus it may be appropriate to ask 'what', 'why' and 'how' *before* asking 'when' (Yow, 1994). Additionally, recall can be improved by providing subjects with a 'temporal reference system'. Timelines or event calendars allow the subject to order their thoughts and provides a frame of reference as an aid to memory. This can be a weekly, monthly or yearly figure depending on the area and period of interest (Martyn and Belli,

2002; Friedenreich, 1994; Means et al, 1991). Such devices help subjects to use events that they can recall easily (such as births, deaths and marriages) to date more accurately other events in their life. Where the researcher is interested in the routine activities of a subject's life, such as typical working patterns, recall can be assisted by the use of 'flashbulb' memories. This is where the extraordinary and unusual becomes linked with the routine and mundane. Examples of such events include people being able to remember exactly what they were doing when they heard that President Kennedy had been shot, or that Diana, Princess of Wales had died, or when the World Trade Centre was attacked.

Development of the Lifegrid Method

The lifegrid method was developed during extended interviews within a general medical practice setting (Blane, 1996) and validated in a study (hereafter referred to as 'the validation study') which compared information contained in two historical archives with retrospective information collected by lifegrid interview (Berney and Blane, 1997). The archives were the records of a survey of childhood diet and social circumstances, conducted by Boyd Orr in 1937-39, and the Mass Observation collection of diaries and questionnaires from the 1939-45 war. A sub-sample of Boyd Orr respondents and Mass Observation diarists were traced to their present day locations by means of the NHS Central Register. Those who gave us permission were visited in their own homes in 1996 and completed a lifegrid interview. Lifegrid information from the periods covered by the archives was compared with the same items of information in the records. In this way, contemporaneous information from, respectively, 1937-39 and 1939-45 could be compared with the same items of information from the same individuals collected by lifegrid some 50 years later. It was found that simple occupational and residential information, such as father's occupation, residential address and housing circumstances at the time of the original survey, were recalled with useful accuracy. Details of childhood diet and childhood illnesses were recalled less well.

The Lifegrid Interview

Prior to the interview, the interviewer should ideally know at least some basic facts about the subject. Of most use would be the subject’s date of birth. This allows the interviewer to prepare the lifegrid sheet before the interview. In the validation study, an A3 sheet of paper was used. This was necessary as the age of the subjects meant that six or seven decades of information was to be completed. It was decided in the development stages that we would only focus on residences and occupations that lasted for more than six months. It was felt that the interview could potentially become too lengthy and confusing if subjects were asked to recall too many items. Therefore, for people who had spells of frequent job changes or periods in temporary accommodation, they were asked to describe the *typical* circumstances of each. The bulk of the interview was concerned with the conditions in residences and occupations held for longer than six months.

In the example that follows, we see a lifegrid being completed for a man born in 1925. In the studies during which the lifegrid method was developed, the researchers used an A3 sheet of paper on which to record the data supplied by subjects. The areas of interest were residential and occupational histories.

At the start it is emphasised to subjects that *initially* it is not necessary for them to provide complete accuracy as we will be coming back to look at dates of change of residence and change of occupation (or changes within occupation). On the lifegrid sheet, the left-hand timeline has marked on it a number of notable public events. In the worked example that follows [Figures One - Four], we see a section of a lifegrid being completed for a man born in 1925. The public events marked on this lifegrid are: the General Strike of 1926; the start and end dates of the Second World War; the Suez crisis of 1956 and the Kennedy assassination in 1963. If during the course of the interview the subject spontaneously mentions another notable event, one that they themselves use to date events in their life, that too is entered on the ‘External’ timeline for possible use later in the interview.

Figure One

	<u>External</u>			
1925				
	General strike			
1935				
	War starts			
1945	War ends			
1955	Suez crisis			
	Kennedy shot			
1965				

The second timeline is labelled ‘Family’. The subject is asked to provide dates for the birth of their siblings and children, marriages and deaths of family members. They may be prompted by the interviewer, ‘was that before or after the War?’

Figure Two

	<u>External</u>	<u>Family</u>		
1925				
	General strike	Brother born		
1935				
	War starts	Sister married		
1945	War ends			
		Married		
		Son born		
1955	Suez crisis			
		Father died		
		Daughter born		
	Kennedy shot	Mother died		
1965				

The third timeline is labelled ‘Residential’ and beginning with the house that they were living in when they were born, the interviewer then asks them to list all the residences they have lived in and the years that they moved house. Here, once again, the interviewer can provide prompts.

Figure Three

	<u>External</u>	<u>Family</u>	<u>Residential</u>	
1925			6 Oak Street, N16	
	General strike	Brother born		
1935				
	War starts	Sister married		
			Army- various residences	
1945	War ends			
		Married	42 Chapel Terrace, N16	
		Son born	10 Effra Road, N16	
1955	Suez crisis			
		Father died		
		Daughter born	15 Ascot Drive, W10	
	Kennedy shot	Mother died		
1965				

The final timeline in this example is labelled ‘Occupational’. As well as noting changes between occupations, subjects are asked about changes in their working situation whilst at the same employer, so that promotions and changes in work environment can also be noted.

Figure Four

	<u>External</u>	<u>Family</u>	<u>Residential</u>	<u>Occupational</u>
1925			6 Oak Street, N16	
	General strike	Brother born		
1935				
	War starts	Sister married		Messenger, Newell's
			Army-various residences	Army-Private
1945	War ends			
		Married	42 Chapel Terrace, N16	Turner, Armstrong's
		Son born	10 Effra Road, N16	Foreman, Armstrong's
1955	Suez crisis			
		Father died		Manager, Jenner's
		Daughter born	15 Ascot Drive, W10	
	Kennedy shot	Mother died		
1965				Self-employed

Other studies, which have used the lifegrid, asked subjects to complete a fifth or even a sixth line, the final number of lines is ultimately dictated by the individual strategy of the researcher and how they

wish to modify the lifegrid for their own purposes. In the development studies, once the above four lines had been completed the subject was asked to then describe in detail the living conditions at the first residence (number of rooms, access to hot & cold water, location of toilet (if any), signs of damp, proximity to factories (pre 1956 Clean Air Act) and main roads (post 1956 Clean Air Act)). They were then asked about their job description and working environment in each of the listed occupations. Levels of job autonomy and physically arduous labour as well as the presence and level of any fumes and dusts were noted. It is during the completion of this part of the interview that another advantage of the lifegrid becomes clear. In the Boyd-Orr interviews, of particular interest to the study was the lifetime exposure to the hazards to health listed above. It is here that accurate dating became important. With the completed lifegrid in front of him/her, the interview then frames the questions on hazard exposure using the various cues that the grid provides. In the example above, a question on how long the subject worked as a turner might be phrased accordingly:

- Q. You said that you started work as a turner at Armstrong's in 1947.
- A. That's right.
- Q. And this was the same year that you got married and moved to Chapel Terrace?
- A. That's right.
- Q. And you worked as a turner for two years and were made a foreman when your son was born?
- A. I was made a foreman just after my son was born yes.

By asking questions in the above manner, the interviewer not only elicits confirmation of the length of time the subject was a turner but is also receiving confirmation that the other information is also correct. So the date of moving house and the birth of his son are also reinforced by reference to the period he spent as a turner and his promotion to foreman. It is during this stage of the lifegrid interview that the 'paper and pencil' nature of the method becomes useful. When a subject finds that the date of an event 'can't be right' when the other information is put to her/him, the interviewer can easily make adjustments. So using the above

example once more, the following exchange may take place:

- Q. Was it before or after your father died that you became a manager at Jenner's?
- A. Now hang on. Let me think about that. We moved to Ascot Drive when I became manager. It was the promotion that let us afford the bigger house. I was still a foreman when my father died. So what year is that.
- Q. Well you moved to Ascot Drive in 1959...
- A. That's right, I did. Well done.
- Q. And that was the same year that your daughter was born.
- A. So it was. So it must have been '59 that I became manager.

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The above exchange, as well as illustrating the how lifegrid makes the cross-referencing of data easier for the interviewer, also shows how having a host of biographical data to hand makes the building of rapport much easier. The interviewer has gone from a position of knowing very little about the subject to a position of knowing and linking a great deal of important biographical data. Subjects are often pleasantly surprised by this and comment favourably on the interviewer's rapid grasp of their life history.

Discussion

The lifegrid method has been shown to enhance recall with a wide range of subjects and on a broad range of topics. Dementia offers an extreme test of the lifegrid's advantages. The ability to improve a subject's recall would be particularly advantageous in the presence of dementia. It is also the case in such research that methods should be flexible to a subject's needs and abilities. The validation study showed that often it is not necessary or indeed possible to focus on the very small details of a subject's life. It may often be beyond the ability of the subject to recall every brief residence or temporary job and there may simply not be enough time for the interviewer to ask for such information. The completion of the event data which makes up the lifegrid can be completed in a relatively quick time (on average 15 minutes during the development study). It is necessary to decide what data will be collected at this part of the

interview. We chose, for example, to only ask about the births and deaths of immediate family.

Part of the challenge of research in this area is that there is no standard profile for dementia. It is also the case that dementia affects both short and long term memory. Those involved in the care of people with dementia often look for what Gibson (1994) has called 'islands of lucidity'; intact parts of a person's memory which may form a basis of mutual understanding. An extensive literature exists on the topic of the 'life review' as a therapeutic method used with people with dementia. This is the process of going back over past events in an individual's life and provides for some the ability to gain new insights or achieve resolution of incidents which may have been troubling them greatly (Garland, 1994). Seen from this perspective, the methods which draw on reminiscence serve a dual purpose. They facilitate recall in order for the interviewer to be able to collect the data required whilst simultaneously providing an enjoyable experience for the subject; an experience which can continue to have positive benefits long after the interview has ended (Mills, 1997). As Gibson notes, through reminiscing, 'the rich colour and fine-grained texture of a person's life' is revealed.

Two points are worth noting here. Firstly, from a research point of view, it is often precisely this 'fine-grained texture' that is of interest. In the lifegrid validation study, it was the details of the subjects' living and working environments that were central to the analyses. Secondly, from a therapeutic point of view, Gibson found that many key workers involved in the care of patients with dementia felt they could put life history data obtained from a subject to uses which would be of benefit to both. Such uses included designing living environments in a manner more likely to meet with the subject's approval and scheduling routines to be more in keeping with what the subject is familiar or at ease with.

Mills notes that memories of the self remain strong throughout life and can persist in the presence of dementia. Such personal memories (the 'family', 'residential' and 'occupational' lines on the lifegrid) appear to have a durability that outlasts those memories of 'world' events (the 'external'

line). Whilst this may not be true for all subjects in all situations, the advantage of the lifegrid is that it draws on memories from a number of sources, each mutually reinforcing the other. It also allows the interviewer to note those memories which have an emotional resonance for the subject, and use such memories as a prompt or aid to recall later in the interview.

Our experience of using the lifegrid method with people with dementia is very limited and as such, we are presently unable to make definitive statements about its suitability for use in dementia research. However, based on the use of the method so far and also the evidence from a range of multi-disciplinary studies which informed the development of the method (i.e. the psychology of memory, epidemiological studies, oral history research methods) we can offer some impressionistic guidance and suggestions for future applications of the method.

The lifegrid approach is extremely flexible and allows for the subject to determine the recall cues. The researcher can quickly identify those areas which assist the recall process whilst simultaneously developing rapport. This should not be understated. Interviewees may feel confused by the questions and wary of the interviewer. In facilitating a more rapid development of familiarity than is the case with a more traditional structured interview, the lifegrid puts the subject at ease. In this more intimate and relaxed atmosphere, the subject is more likely to be both willing and able to recall the information that is of interest to the researcher.

It is also likely to be the case that the process should be as simple as possible to achieve the research aims. In the development study interviews, the subjects were asked information on a fairly wide range of topics and covered the entire life course. It may be asking too much of some subjects to expect them to be able to maintain the level of concentration and commitment required for a life course study. In one interview, a subject who was recovering from a recent stroke said that all the questions made her 'head hurt'. Thus, even with the aid of a range of memory cues, recalling events in the distant past may be too difficult for the interviewee to undertake.

The completion of the lifegrid is a joint endeavour by both interviewer and subject. It may well be the case that with the current generation of subjects with dementia that the familiarity of a 'paper and pencil' approach is preferable to the detachment of an interviewer sitting with a laptop computer. Sitting side by side with the interviewer, the subject can see the lifegrid evolving and feels more intimately involved in the process.

Parry et al (1999) found that factors other than recall ability may play an important role when researching older populations. Often the poor health of subjects, and the fact that the periods of recall under discussion in the elderly can be much longer, means that the ability to progress through the interview at a pace and direction of the subject's choosing is another strength of the lifegrid approach. The method has been used in a wide range of studies. Edwards and colleagues (personal communication) have used the lifegrid when collecting data for a case control study looking at the relationship between lung cancer and living close to heavy industry. The average age of subjects in their study was 65 years. Dawson et al (2002) have used the method in a study looking at the relationship between symptomatic knee osteoarthritis and past high heel usage in women. The average age of subjects in their study was 63.5 years. In a further study looking at members of the Boyd Orr cohort (Berney et al, 2000; Holland et al, 2000), nearly 300 subjects aged between 63 and 78 years old were recruited and completed a lifegrid interview covering residential and occupational histories.

In summary, the lifegrid method of collecting information retrospectively has been shown to collect simple socio-demographic information with useful accuracy after 50 years. So far the method has been used mainly in social medicine research. The flexibility of the method, combined with its ability to enhance both recall and rapport, suggest that it may be of use when interviewing older people with dementia.

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