Narrative and knowledge development in medical ethics

Philip Tovey  University of Leeds, Leeds

Abstract
The role of individual life accounts has been promoted - largely through what has come to be described as narrative ethics - as important to the practice of medical ethics for a number of years. Beyond this the apparent incompatibility of personal stories with scientific procedure has limited their use. In this article I will argue that this represents a serious under-utilisation of a valuable method for researching ethical dilemmas and the settings in which these dilemmas are played out. Life stories need not simply provide a stimulus to scientific research but can in themselves yield intellectually robust evidence on the general as well as the particular. By drawing on the rigorous methods developed elsewhere, personal accounts not only allow us to “enter the world of the sick person” but allow us to do so in such a way as to contribute to empirical and theoretical knowledge.

(Keywords: Life stories; empirical research into ethics; methodology)

This paper is concerned with the role of life stories in medical ethics. It is not, however, a piece of narrative ethics concerned with the practice of ethics, in which the immediate objective is the appropriate resolution of an individual ethical dilemma. It is instead an argument that the power of life stories as a research tool, as a source of insight into ethics or about the contexts in which ethical dilemmas are played out, has been seriously overlooked and under-valued. It will be argued that the fusion of the emphases of narrative ethics with rigorous methods formulated within sociology provides the potential for narrative to be a valuable part of academic enquiry in what are frequently complex and sensitive areas.

Issues surrounding the role of the imagination, the need to understand the subjective experience of the patient, and the relevance of individual stories have been raised recently in this journal.\(^1\) 2 Although my concern with life stories as an empirical research strategy is in many ways quite distinct from the focus on literature in these papers, Gillon’s article in particular presents arguments about personal stories and their relationship with science which are of fundamental import here. As a consequence, at several stages in this paper, I engage with those ideas of Gillon in arguing for a re-assessment of the value of life stories.

Following a brief review of the key elements of narrative ethics and some central similarities and differences with the emphases of the life-history approach, the bulk of the article will be concerned with reconciling the seemingly irreconcilable: the use of isolated individual experience, and the need for “good science” which contributes to knowledge in a way which extends beyond the peculiarities of one specific situation. To this end, I will describe the principles and practicalities of using the life-history approach (the terms life history and life story are used interchangeably in this paper and refer to the same method), illustrate these with a worked example of how it has been successfully used to generate knowledge in an area beyond medicine, and go on to suggest a specific application in the empirical study of medical ethics.

Narrative ethics and the life-story method: similarities and differences
Reference to narrative in consideration of medical ethics characteristically occurs in relation to what has been described as narrative ethics.\(^3\) A significant literature has been established on a range of issues relating to narrative ethics including discussion of: the meaning(s) of the term itself; its relationship with phenomenology;\(^4\) and with Christian ethics;\(^5\) the relevance of post-modernist analysis;\(^6\) and, of course, its relationship with literature.\(^7\) However, these are not the concerns of this paper. As will be seen, life stories and narrative ethics have a degree of complementarity but are not interchangeable; despite similarities, the two approaches are engaged in fundamentally different projects.

Thus, there are both points of convergence and divergence between the essentially philosophical approach (narrative ethics) and the fundamentally sociological one - life-story method. Four
elements of narrative ethics form the basis of similarity between the approaches. First, and not surprisingly, personal narrative rather than a pre-identified framework is central to the analysis. Second, this narrative holds centre stage in the decision-making/dilemma-resolution process. Third, the approach is all about the achievement of an understanding of the meaning of the situation for those involved. And fourth, there is a recognition that it is only through knowledge of the personal, cultural and social context that the most appropriate ethical solution can be reached.

These principles have clear points of compatibility with streams of sociological thought which have been more or less influential at various points in the twentieth century. In particular the centrality of understanding an individual’s (or group of individuals’) world from his/her perspective rather than from one externally imposed has formed the basis of all classic applications of the life-history method. But there is a quite clear point of departure for the life-history approach. It is that while the practice of narrative ethics is all about working towards a satisfactory resolution for an individual based on an awareness of that individual’s life, the point of utilising life stories as a method is to work towards the uncovering of the scientifically general which can advance knowledge of patterns of action. In turn, this has the purpose of contributing to the base of knowledge within which decision-making as an interplay between professional(s) and patient takes place.

Life stories and knowledge formation - beyond the individual

EVIDENCE-BASED MEDICINE

As was noted by Gillon, this is an era in which “evidence-based medicine” (EBM) is increasingly directing research and practice, and the randomised controlled trial remains dominant in the collation and definition of that evidence base. However, the potential offered by qualitative methodology to this process is also receiving increased attention. What is crucial, if the potential of this qualitative input is to be realised and become meaningful for the “modern scientific doctor”, is that the rationale which underlies it is properly understood and that its role is not restricted to that of descriptive adjunct (for instance, as the source of quotations to flesh out statistically significant findings) to the “harder” sciences. And far from providing an excuse for sloppy science, this demands rigour of the researcher - a rigour which, for example, provides the means for the elevation of individual stories to the point where a contribution to the evidence base can be made.

THE SCIENCE OF MEDICINE; THE ART OF MEDICINE

In parallel with this discussion of EBM, Gillon highlighted the need for practitioners to “enter the world of the sick person”, with the objective of gaining access to the experience of being the patient. He argues that the art of medicine should be integrated with the science of medicine in pursuit of a deeper understanding and a more appropriate practice. This position is advanced in relation to the use of literature as a route into that deeper level, as a means of reaching the subjective or the imagination. In such a situation the split - between a science of medicine grounded in evidence formulated in ways consistent with the experimental paradigm, and literature born of personal reflection - is appropriate. But if the emphasis of the quest to extend “our understanding of the depth and variety of human experience, our ability to share in the experiences of others ...” is able to be shifted to embrace systematic empirical research, the art and science of medicine become integrated, if those concepts are to be understood in terms of the ability to offer both insight and scientific procedure.

This has the benefit of providing the means to foster the imagination, not on the basis of an abstracted interpretation of events but on the basis of evidence drawn from those undergoing the experience; evidence which can be specific to whatever the concerns of the researcher or ethicist are: an historically specific setting, a social and cultural context or an organisational location, for instance. The centrality of empirical knowledge generation allows for insight to be pursued not at the level of uncovering fundamental human truths but in terms of the construction of meaning and experience for a particular individual or group of individuals at a given historical juncture and in response to specific circumstances. Insight into the experiences of pregnancy or suicide attempts, for example, is gained from the perspective of those involved in that life event, and not from the imagination of the writer. It is not that literature is an inappropriate source of insight on these matters; it is rather that its limited scope can be complemented by the integration of art and science which it does not itself look to achieve.

LIFE STORIES AND ‘GOOD SCIENCE’

At this point I want to develop my argument a stage further. To now, my concern has been to highlight the value of gathering empirically the life stories of those who have experienced or are experiencing a given condition or event. What I have
yet to address is how this can be squared with “good science”, how in fact such data (though by its nature more socially and historically specific) is any more generalisable than the literary sources which I argue can complement.

For Gillon individual stories “are insufficient for medical ethics . . . they need to be used as stimuli and bases for research and reflection leading to generalisable conclusions in philosophical medical ethics”. In this view, stories are necessarily outside of the research process; they provide a pre-liminary stage in which research ideas are formulated, one which is followed by, but never forms a part of, scientific procedure.

This is a view which makes a good deal of sense if the stories that are being considered are those of literature, being made use of in isolation from any conceptual framework for their analysis. And, Gillon rightly stresses the difficulties which will be produced if the imaginative use of a case is not grounded in broader science. But, and this point is central to the argument for the value of personal accounts, the necessary scientific input need not be a separate phase from the utilisation of stories, but should be an integral part of that use - with scientifically valid conclusions evolving from the analysis of such stories. This will become clearer with the following overview of the principles and practicalities of the life-history method.

LIFE STORIES: PRINCIPLES AND PRACTICALITIES
For Denzin, “The basic theme of any life history is the construction of a set of explanations that reflect one person’s or one group’s subjective experiences toward a pre-determined set of events . . . . It is important to keep in mind that the basic theme of the life history is the presentation of experience from the perspective of the focal subject or subjects. Their world must be penetrated and understood. Once it is entered, the observer lays out the critical-objective experiences relevant to that world and then has his [sic] subject react to those events”. By locating the reaction to objectively similar events within the whole life process we are able to trace patterns of influence - notably those shaped by varying social and cultural backgrounds and the individual’s mediation of those - which affect the formation of differing modes of social action. The life history should be seen as a means of access into areas of social life.

The empirical and theoretical questions to which the researcher is seeking answers will necessarily inform decision-making about both the nature of informants and whether specific aspects of lives will be afforded more or less prominence. For instance, if researcher interest lay in examining the extent to which the four principles impact on the actions of primary care counsellors in helping in the decision-making of those facing immediate dilemmas, then substantial attention to the working lives of these counsellors could be expected. This would constitute a focused life history - that is, a focus on the decisions and actions in one setting in the context of a knowledge of counsellors’ lives as a whole. The decision about which counsellors to study will similarly be influenced by the perspective of the researcher. It might be that informants known for a particular mode of therapeutic practice might be of interest, those from a particular professional body, or simply those with no greater connection than practice in a primary care setting. The point is that selection is essentially bound up with the underlying questions of the researcher.

The central means of data collection are the written life story and the detailed interview. I would argue that they are most effective when used in tandem, as a significant level of autonomy can be given to subjects to shape the nature of analysis in the opening phase, and the researcher has full opportunity to explore unexpected themes in the second. While subjects can profitably be offered broad themes (post school life, professional life etc) which they might wish to address in their written accounts, it should be made clear that the interpretation of what is important rests ultimately with them.

The approach to data analysis has similarities with that used in other qualitative methodologies such as case studies and ethnographies. However, in the 1980s Bertaux adapted these principles specifically for the analysis of personal accounts, and these have since been modified and extended for use in settings beyond those originally identified.

It is useful to see the process involved as one of proposition development. The researcher may begin with a broad theme (for example, forms of counsellor role in relation to the primary care team); analysis of the first life history might lead to a working proposition (a preliminary statement) about that theme. With each subsequent life history the objective is to subject that proposition to rigorous examination, to a constant search for negative cases which demand its revision. Properly performed what results is not a yes/no response to a simple hypothesis but a complex proposition or set of related propositions which incorporate and account for the range of actions relating to each theme. The aim of the procedure is to reach saturation - a stage at which new accounts make sense within existing propositions and therefore do not require those propositions to be modified further.
The autonomy (discussed above) afforded to informants results in the emergence of subject-directed themes and propositions to sit alongside those identified at the outset. These are, of course, explored in the same way, and as will be seen later are particularly important when studying areas with a limited pre-existing knowledge base.

Given the relatively small number of informants and the essentially inductive nature of the method queries about the generalisability of results, and the reliability/validity of the approach might well be raised. In relation to the first of these, it is important to appreciate that the generalisability of the results is dependent less on arguments about degree (is it less generalisable than statistically supported evidence?) and rather more on a recognition of the fundamentally different interpretation of generalisability which is at the heart of this method. No collection of life stories is ever likely to be gathered in such a way as to constitute a representative sample. Because no population is being mirrored, no generalisation to any given population is attempted. Instead what the rigour of the method is directed towards is a generalisation to theory - a means by which an existing expectation, understanding, or body of knowledge is exposed to, and revised on the basis of, new empirical evidence drawn from a particular site of activity. That modification then occurs in relation to the characteristics of the study in question and those involved in it. The object is then a “progressive elucidation” of ever-changing socially located events rather than a fixed/generalised knowledge of them.

The question of the relevance of notions of reliability and validity to the life history has been neatly summarised by Plummer. He argues that the pursuit of reliability - making the study replicable - is largely inappropriate. He states: “...validity [ensuring that the study is measuring what it purports to] should come first, reliability second. There is no point in being very precise about nothing. If the subjective story is what the researcher is after, the life history approach becomes the most valid method... it simply will not do to classify, catalogue and standardise everything in advance, for this would be a distorted and hence invalid story”.

THE LIFE HISTORY AND KNOWLEDGE FORMATION: A NON-MEDICAL EXAMPLE

The sensitivity and relative isolation of the public school sector produces a research context not dissimilar to that facing an empirical ethicist - both in relation to difficulties of gaining access to empirical evidence, and because of the innumerable moral and political issues which impact on the study of the area. My own research on the sector can be described both to elaborate on procedure and to illustrate the potential of the approach.

The subjects of the research were 18-21-year-old ex-public school pupils. The rationale behind selection was to permit accurate recall of recent events whilst at the same time freeing respondents from the restrictions of the school environment. It is this latter point which underlines the benefits of the method over the obvious alternative - ethnography. In such controlled environments it was simply unrealistic to expect either unlimited access to areas of interest or that pupils would be prepared to discuss the kinds of sensitive issues unveiled by life histories, given the extent of formal and peer pressures to conformity (for example, accounts relating to pupil and teacher sexuality and the relationship between that and how schooling was experienced were freely given in life histories but it is hard to imagine how this would have happened in the school setting). Sixteen pupils - a figure settled on during the course of the study as a number sufficient to confirm propositions - provided written stories. The only guide given was to include information on: family life, early schooling, later schooling, and post-school life. How this was applied reflected the concerns of individual respondents. It was through these life accounts that what became the defining focus of the study - pupil sub-groups emerged as a theme (see below). Follow-up interviews were held. The combined method yielded around a third of a million words of text for analysis. In keeping with the approach outlined above, with the transcription and analysis of each account so each theme was re-examined and each proposition re-assessed. The complexity of the previously under-researched themes resulted in 70 propositions being followed through to study completion.

The way evidence emerged which subsequently reversed sociological thinking about elite sub-cultures is illustrative of the power of the approach. At the outset of the work very little was known (academically) about the nature of pupil experience of public schools, patterns of hom-school interaction, and crucially the relevance of existing theory to explain these. Existing theories of the processes of schooling had evolved largely from work in the state sector and so could not take into account the specifics of this context and those involved in it. This was certainly true in the case of “sub-culture” theory. Without going into too much detail, sub-cultures were a hot topic of late 70s and 80s sociology. Virtually without exception this interest centred around the idea of...
working-class sub-cultures in schools as a reaction against an education system grounded in a culture which was alien to them. Not surprisingly, because of its reliance on “opposition” and “resistance” such theory had nothing to say about public schools. However, the die was cast, and sub-cultures often with a close association with aspects of popular culture, were seen as a working-class issue. Indeed, the only contemporary study to talk of sub-cultures in the context of public schools simply adopted the line of looking for opposition, reported none existed, and therefore that neither did sub-cultures.

For this reason sub-cultures had not figured significantly in my early clarification of issues to pursue. However, as accounts came in there was frequent if irregular mention of tightly-knit groups of pupils whose identity and sense of belonging were firmly established. These accounts came from those involved and those excluded. The issue was consequently picked up and systematically addressed (the emerging picture was raised and challenged) in each of the interviews and what emerged were (sociologically) startling accounts of the import of these groups. In short, a fundamental revision of sub-cultural theory to account for actions in elite settings was required by the evidence. The assumed significance of popular culture, the assumed link with opposition, and the assumption that the most important manifestations of sub-cultures occurred amongst the disaffected were all seen to be simplifications. However, the vital importance of understanding the life process up to and throughout the period of particular interest could not have been more strongly confirmed.

This is, of course, no more than a flavour of the theoretical revision which resulted. The key point is that existing knowledge and theory was totally incapable, not only of predicting this outcome, but of identifying sub-culture as an issue worth exploring at all. Allowing subjects to shape topics of discussion in the context of the life-history analysis both introduced sub-culture as an issue to address, and crucially, provided the means to do this within an appropriate personal and cultural context. Without knowledge of this background the inter-generational basis of these groups, which made them so powerful, would have been missed, and a range of school processes which existed around them would have been inappropriately interpreted.

CHANGING ETHICAL DILEMMAS IN PRIMARY CARE: THE CASE OF THE TRIPLE TEST

It is, of course, the way this theoretical advance was made possible rather than the subject matter itself that is of particular relevance here. The ability to “enter the world” of people, to provide them with the means of defining the issues, and then to explore the way in which personal mediation of events relates to personal, social and cultural context are all both fundamental and transferable cornerstones of the approach. While the selection of subjects, themes and empirical and theoretical issues will change, the potential to explore a common life event in detail will not.

For an example of its potential I will turn to one part of health care which is currently undergoing substantial change - in terms of the character of professional roles and responsibilities, the organisation of provision, the nature of treatments etc - primary care. This trend has been intensified with the push towards a higher profile for primary care in the National Health Service (NHS). Not surprisingly we are beginning to identify a range of ethical issues accompanying such changes, and importantly, a limited awareness of how far existing knowledge and theoretical frameworks will be meaningful to these.

One such area is the shift in attitudes towards childbirth, based on a move away from hospital-based provision and towards that based in the community. A possible consequence of this may be the increasing use of the Triple Test (for Down’s syndrome screening) for a wider range of women in primary care settings; a matter that is currently a topic of debate.

Establishing empirical knowledge about how this is being personally mediated by both professionals and patients would necessarily inform the inevitably complex decision-making process surrounding emergent ethical dilemmas. Although we might well proceed on an assumption that key issues here would be personal beliefs about abortion, the (late) abortions implicated by the process, the relative unreliability of the test etc and that these might be profitably looked at in relation to “autonomy” or other pre-identified principles, as was seen in the case study above, imposing expectations in this way can both obscure issues and distort analysis. Moreover, without empirical study the inevitable complexities introduced by the inter-relationships between personal decision-making and cultural or religious variations would necessarily be bypassed.

So, what is needed is a route into this aspect of the changing medical landscape which: does not pre-judge the character of salient issues, provides a means by which theoretical assertions can be examined (of, for instance, the “sophisticated utilitarianism” of decision theory recently discussed in relation to this issue), allows socially located personal experience to inform analysis, and
which permits an understanding of key issues and processes which takes full account of differences but is structured to lead to generalisable (as discussed above) conclusions. The life history provides this. Finally, it can be expected that changes occurring in parallel to those in primary care, such as in community care, social care, and, of course, hospital-based care, will similarly throw up innumerable new circumstances of dilemma. Human response to these changes will not be constant but will evolve in relation to fluid social and cultural influences. Personal accounts, by their very nature, are able to trace how such circumstances are being mediated.

Concluding comments
This paper has centred around the proposition that not only do personal stories offer a valuable source of insight into the empirical reality of situations and events, but more, that through the use of established sociological procedure we are able to make the leap from the ideographic to the generalisable. In this way the argument that “stories are insufficient for medical ethics” becomes restricted to those stories of literary origin. With empirically gathered stories, established theories, principles and expectations are opened up to the challenge of accounting for numerous real-life situations and experiences. And, resultant theoretical revision is rooted firmly in those experiences of each situation’s key players.

The aim of using the approach, then, is not in itself to solve medical dilemmas, or to promote “appropriate” values and consequent action; the approach is instead a means to extend knowledge about “patient worlds”, to “enter” those worlds empirically and thereby contribute to a multidisciplinary and multi-faceted approach to these complex issues which is already incorporating qualitative research data. Gillon concluded with a call for an alliance of medical science, philosophical medical ethics, and individual stories - I, therefore, conclude similarly, though with a call for a re-consideration of the nature of the contribution to be made by those stories.

Philip Tovey is Senior Research Fellow at the Centre for Research in Primary Care, University of Leeds, Leeds.

References