

Literature in Bioethics. A Cognitive Approach

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Abstract

This contribution argues in favour of the use of literary texts in bioethics, in order to expand standard methodologies in the field. It also defends a cognitive approach to the issue, since stories might provide some significant information to analyze certain difficult cases. In fact, specific data concerning patients with Alzheimer's disease are not always available for open discussion, and in such cases one wonders how to deliberate about practical problems and ethical dilemmas. The thesis is that some stories and texts could offer indirect information about the experience of illness and clinical practice. For instance, the case of Mrs. Bayley is well-known; there is information about her last years with dementia, she was a famous author, and we have Mr. Bayley's testimony. However, this is quite exceptional because of its literary form. Here three arguments are provided to support the cognitive approach to the issue; namely the obvious limits of communication about illness and pain, the dynamics of practical deliberation, and the restricted use of personal data.

Keywords: Bioethics; narrative; literature; case method; I. Murdoch

How might literature improve bioethical analysis? There are several reasons to justify the standardized or even occasional use of narrative and, especially, of literary texts in bioethics. However, this article is limited to exploring the cognitive approach to the question, since it focuses on practical deliberation with limited data. It argues in favour of the use of literary texts in bioethics, in order to expand the standard methodologies, from principlism to casuistry, because stories - both biographical and fictional - may provide indirect but valuable information for the analysis of certain somewhat problematic cases. In some circumstances, direct information is not even accessible. In fact, specific data concerning patients with cognitive impairments, due to Alzheimer's disease for example, are not always available for open discussion. In such cases, how can one deliberate about practical problems and ethical dilemmas? In this sense, the article proposes that stories and literary texts could offer indirect information about the experience of illness and clinical practice. It suggests three arguments to support this cognitive approach to the issue: the limits of communication about illness and pain, the complex dynamics of practical deliberation, and the restricted use of personal data. Perhaps a story, a real one, could exemplify how literary texts may contribute to a closer understanding of ethical dilemmas in clinical decision making in tight situations.

A Case and a Method

Mrs Bayley's cognitive competences deteriorated visibly. She was no longer able to deploy the rich vocabulary she had previously used. Her routines had to change; she felt disoriented and depended more and more on her husband for her daily needs to be met. He kept some notes about these years, with his wife in the grip of Alzheimer's disease until she died. Then, because he was a writer, he published the whole story. His wife had also been a writer and indeed had been widely read; Mrs. Bayley was in fact Iris Murdoch, a philosopher and famous author of novels and plays. Her last book, *Jackson's dilemma*, disconcerted literary critics and many readers; after her diagnosis - she was seriously ill, suffering from dementia - people began to detect the fatal traces of Alzheimer's disease inside the novel and its shaky outline. Mr. Bayley described how the disease had changed their lives and how it had stolen Iris' memory and her very special personality. Thus, we have information about her and her last years thanks to her last novel and to Mr. Bayley's testimony. Nevertheless this case seems unique and almost an exception. Indeed, books like *Iris* (Bayley, 2000) are rare. In general, the literary expression of the outcomes of dementia is very unusual.

The book exemplifies how writing could give some form to episodic information about the devastating experience of patients and caregivers living under the pall of Alzheimer's disease. The question is how could literature improve bioethical analysis? Literary texts would form part of a methodology to deliberate about and disclose certain aspects of difficult issues, since narrative – from biographies to fictional work - could forge stories concerning patients, professionals, and caregivers “as if” these stories were real. In fact, information related to actual cases is usually protected and hence access to clinical data is restricted; moreover, it should be restricted for the sake of people involved in clinical practice or in research. In general, specific data about cases are not available to everyone for open discussion or for teaching and training. Accordingly, how shall one understand difficult situations and dilemmas without highly specific and nuanced information? In this context, stories, including fictional stories and literary texts, could offer some insight into the experiences of illness and suffering. Sometimes, they also show alternative ways to face moral dilemmas in clinical practice. How is this done? The literary form imposes some distance and for this very reason it can be helpful in reflecting on the complexity of pain and illness. In sum; there is or could be information, some knowledge in fiction. The cognitive thesis about the role of literature in bioethics defends that the veil of writing could make some sense out of difficult issues, therefore it expands the resources for bioethical analysis. There are, of course, other narrative formats such as the cinema, television, painting, etc. that could provide indirect information and, perhaps, help to refine practical arguments about real cases. For example, the well-known Prinzhorn Collection in Heidelberg shows how important paintings and art in general can be for patients with mental diseases and for their clinical treatment. However, in literature production, language and reception are completely different; images and external elements cannot divert us from personal and silent reflection. In this sense, the veil of writing creates a space to think about possible courses of action.

Three Arguments

Iris had serious difficulties in remembering things and with language. She was plagued by a multitude of problems with her daily routines, such as eating, sleeping and personal hygiene. Her relationships with friends and former colleagues deteriorated radically, and her activities became less frequent and simpler; she was reduced to taking only short walks or simply watching the television. On top of this, she hated her medication and the medical supervision she was receiving. The household fell into disarray and this called the attention of the social services. However, it was clear that Iris felt comfortable at home and that she trusted her husband. The disease left its scars on both the couple and on the household. Despite this, Iris remained there, except for the last months. Her physician recommended a clinic, because her health had substantially worsened. Finally, she contracted bronchopneumonia and died. (Bayley 2003, p. 437). The information about the case is fairly complete, because J. Bayley published this vivid portrait of her before and during her illness. His books are unique documents, literary texts about Alzheimer's disease and its consequences for both, patients and caregivers.

Dementias, and in particular Alzheimer's disease, affect normal functioning and cognitive competencies. Biographical documents are very uncommon because dementias erode language, memory, and personality. At the onset, patients are able to tell or at least write about their undesired experiences “in the labyrinth” (Friel MacGowin, 1993, p. 9), but ensuing stages of the condition modify all conceivable aspects of their lives (Foley, 1992, pp. 30-43). Caregivers are usually so overwhelmed by their responsibilities that they have too little time or insufficient energy to keep diaries or notes detailing the changes brought about by the illness. In the long run, the use of direct information about patients' experiences of dementias – from inside, as proposed by R. Taylor (Taylor, 2007) to transmit the patient's point of view – is very unusual. Naturally, literature *per se* is unable to replace accurately recorded information, but, sometimes, it may serve to bridge the gap between actual information, medical records – whose use is strictly regulated – and the need to understand what is going on, especially the pressing need to be understood when the disease has affected an individual's personality and the lives of others. Thus, some situations would have to rely on indirect information simply because direct information has been restricted or, for whichever reason, is not accessible. Questions about disease and its consequences therefore remain open, as challenges for bioethical analysis. Literary texts are unable to give the right answers to patients, professionals or caregivers, but to a certain extent they do invite us to explore different perspectives and possible courses of action. They could improve the understanding of ethical questions for experts and non experts as well (Hooker, C., Macneil, P. 2015). Many possibilities regarding this issue have already been addressed, especially in the narrative approach to medical ethics (Charon, 2008, pp. 23-35) and bioethics.

For example, case diagnosis would benefit from a correct interpretation of the facts (Charon, 1992, pp. 115-132; 2006, pp. 191-200) and, of course, from a careful appraisal of the stories told by the patients themselves (Frank, 1995, pp. 115-136). The debate about the role of narrative and the central position of evidence-based analysis in these fields is also very interesting; it explores several arguments about the existential dimension (Fox, Swazey, pp. 361-373) and about another completely different thesis: the scientific foundations of medicine (Thomasma, 1980, 1984; Arnold, Forrow, 1993). The narrative turn of bioethics (Montgomery, 1995) insists on case interpretation in health care (Chambers, Watson, 2005). The empirical turn (Borry, Schotsmans, Dierickx, 2005) usually emphasizes the role of evidences in the medical decision-making process (Sackett, Rosenberg, 1995). Of course, both are relevant for contemporary bioethical discourse. Nevertheless, here the focus is basically on the cognitive approach of literature in practical and ethical issues (Lopez de la Vieja, 2013, pp. 19-33); it is about case information. Accordingly, only three arguments about the matter will be addressed: (a) the limits of communication about illness and pain, (b) the complex dynamics of practical deliberation, (c) the restricted use of personal data and case information.

Communication, Deliberation, and Information

In the above case, the key was the literary presentation of Iris's disease and its progression. We read of the many anecdotes generated by her new behaviour, and, especially, the striking contrast between her current situation and her previous life. All this information is intriguing in that it has form and an internal rhythm. In order to follow this story of declining capacities and losses, readers would require an outline or a coherent narrative, especially when the dementia is hugely disruptive, as in Alzheimer's disease. Why should this be so? The argument about *communication* considers that illness and pain may repel others, or at least elicit indifference in them. The general problem of telling and of listening to an account of painful experiences is that these types of experience usually function as circuit-breakers in communications. Such circumstances are very difficult to explain and it is also difficult to draw people's attention to them. Who is interested in knowing the details about the cruel harm and suffering of others? The dilemmas of communication have already been analyzed by victims and witnesses of atrocities and extreme situations; the dilemma was either to write or to live (Semprun, 1997, Lopez de la Vieja, 1993, pp. 123-139). On the one hand, everyone may at some time be affected by pain and only for this reason people must reflect on the issue. On the other hand, another's pain usually leads to a lack of understanding (Sontag, 2003, pp. 66-84). Dementias will place further barriers to understanding and communication and so we must ask ourselves how the missing parts can be filled in.

The *deliberation argument* holds that deliberation is a complex activity that precedes decision-making. As J. Rawls explained (Rawls, 1973, p. 418), it combines different elements, ranging from rationality to singular experiences, beliefs, and emotions. In bioethical analysis, deliberation about difficult cases usually faces moral dilemmas; for this, it could include some general principles, especially respect for persons as autonomous agents, beneficence, and justice (The Belmont Report, Part B). There are no final answers concerning health care and life, but several decisions about some cases may be quite reasonable if the pros and cons of a given course of action are weighed appropriately. The whole process becomes much more complicated if the patients involved in the dilemmas are affected by dementia; clearly, their competency will be limited by the illness. In these specific circumstances, how can we give priority to autonomous decisions? In the story about Iris Murdoch, it is evident that her autonomy had been substantially diminished by Alzheimer's disease, but she was still able to express – with gestures, curious utterances, and firm stances regarding her wishes -- her preferences about food, clothing and people and, most importantly, about who was to take care of her (Bayley, 2000, p.182). In light of this, the question was how to interpret her will and interests in spite of her limitations in language and competency. In cases like this, how can we obtain “real” informed consent? What happens with the patient's advance directives? How shall we establish a correct balance between beneficence and autonomy?

The *information argument* assumes that the protection of personal data and the restricted use of these are - or should be - an absolute priority in research and clinical practice. Iris Murdoch's case is accessible to everyone because her husband decided to divulge it and write the story; the story of how much Alzheimer's disease insidiously stole from her. Other caregivers don't like to speak about similar experiences or feel themselves unable to do so, and of course health care professionals are legally bound to respect confidentiality. Evidently, the patients themselves are unable to explain their situation owing to their declining memory, reduced language skills and poor functioning in general, and as the dementia progresses it destroys both their minds and their lives (World Health Organization). For many reasons, the use of clinical information is, and must be, regulated and restricted.

So how can one approach an understanding of the true conditions of patients, caregivers and health care professionals?

Indirect Information

Since autonomy is a core principle in bioethics, the special circumstances of patients – such as their cognitive competencies being devastated by a type of dementia (Beck, Vovepohl, 1992, pp. 118-137) – cannot be invoked as an argument to ignore their interests and their fundamental rights (UNESCO, 2005). In fact, several documents, such as the Charter of Principles of 2003 (Alzheimer’s Disease International, 2003), the report of the Nuttfield Council (Nuffield Council of Bioethics, 2007), and the Sitges Document, of 2009 (Boada, Robles, 2009, pp. 13-18), insist on the normative relevance of autonomy and competency. In this sense, they propose that cognitive impairment and other significant problems would not eliminate patient participation in decision-making about care, a flexible assessment of competency, and the levels of or gradual incapacitation. The general idea is that diminished or residual autonomy is still autonomy. These notions seem to be consistent with the normative framework defined by the Convention of 1997 (art. 6), this refers to the special protection due to people who are unable or lack the capacity to give their consent. It then addresses the role of the representative or person in authority who can decide about interventions in such patients. National legislation usually adjusts to this basic framework, as in the case of the Spanish Act of 2002 about patient autonomy (Ley 41/2002, art. 9.3, 16); the Act includes the surrogate decision-making procedure.

The Spanish Act of 2007 (Ley 14/2007, art. 4.2, art. 5) regarding biomedical research mentions the procedure: consent by a representative. This Act is also very explicit about data protection and guarantees of confidentiality, because the general uses of personal data have been regulated since 1999 (Ley Orgánica 15/1999, art. 1). Accordingly, access to health information will require (Ley Orgánica 15/1999, arts. 7.3, 7.6, 8, 9.2 f) express consent by patients (Ley 41/2002, art. 16). In this sense, bioethical analysis has some clear benchmarks; in different countries, the norms in force will indicate how to deal with this kind of sensitive information in clinical practice and in research. In consequence, why should it be necessary to expand on standard methodology in order to clarify questions and dilemmas? In which sense might narrative and literature be useful? First, informed consent and communication in general will remain real challenges for patients without the requisite competency; this is an additional motive to encourage people to prepare documents stating their advance directives, including surrogate decision-making (Buchanan, Brock, 1990, pp. 152-189), before disease or accidents can affect the personal capacities. However, these documents always require correct interpretation - by both representatives (Emanuel, Emanuel, 1992) and health care professionals- because the minds and decisions of patients with Alzheimer’s disease and other dementias tend to fluctuate across a fairly broad range. For example, A. Firlik reported his perplexity about Margo, one of his patients (Firlik, 1991). She seemed content enough with her activities and the therapy, in spite of her loss of memory and competencies. Might she be harbouring some sense of self?

Secondly, taking into account the effects of dementias on people, the difference between “precedent autonomy” (Dworkin, 1993, pp. 218-259; 1986) and “contemporary autonomy” (Dresser, 1995; Quante, 1999) has been controversial. In any case, advance directives could become a problem when the behaviour of patients with dementia suggests that everything has changed for them. What are we supposed to do with the previous document? What does “respect for their autonomy” mean? The general principle is still valid, but it would require some deliberation in these cases, in order to avoid dramatic and irreversible consequences. Moreover, the debate around Mrs. Conroy’s situation shows that representatives and physicians may hold opposite criteria regarding a patient’s best interests and their respect for his or her personal wishes (In re Conroy, 188, 1983; Siegal, 1986) Indeed, the case went to court, where a long legal battle between Mrs. Conroy’s nephew and the medical staff failed to solve the situation in time. Unfortunately, Mrs. Conroy died before the court found that legal representatives are entitled to refuse treatments for incompetent patients. In terms of moral principles, the issue is open; where does the correct balance between autonomy and beneficence lie? Thirdly, direct information about difficult cases such as Mrs Conroy’s may, for plausible reasons, be complete but restricted. It may be incomplete for genuine reasons, but deliberation would continue beyond the available evidence, because the question is how to seek alternatives and determine how to assess the possible consequences of decision making. In this, stories and fictions have a special role. It is remarkable that a UNESCO document recommended simulation as a method for training and education, especially today when resources are so scant (UNESCO, 2012). The conclusion is therefore that indirect information does not actually replace data but it can bring to light some probabilities.

In this sense and for such a purpose, literary texts provide a valid starting point for practical deliberation. In M. Suter's novel, no one had noticed Konrad's dementia until a fire accident highlighted the progressive destruction of his memory and competencies (Suter, 1997, pp. 7-10). After that episode, the general destruction spread to many characters in this story.

Some Conclusions. A Question of Method

The information argument could be elaborated further. According to patients still able to voice their needs, like R. Taylor in the first phase of his disease, the general discourse about Alzheimer's and other dementias must include the key perspective: the patients' points of view. This claim seems almost paradoxical in light of the typical symptom of the illness, such as memory loss, loss of language, loss of relationships, and loss of identity. At this point, when it is impossible to obtain direct information from the protagonists, literary texts could provide some hints about the impact of the disease from the internal perspective. For instance, in M. Suter's fiction, Konrad's behaviour became a real problem for other people (Suter, 1997, 298-299); Alzheimer's disease erased the patient's memories, but at the same time it revealed the ignoble lies and connivances that had supported a high-class family and a successful firm. Afterwards, nothing remained standing; the past overcame the present and the truth was finally revealed; the patient had been deceived throughout his life. His new life began with his illness and the fire accident. The fire metaphor also tells us something significant about the consequences of Alzheimer's disease; it tells us that dementia alters everything; by eliminating feigned relationships, false friends, and minor activities, it puts everything in its right perspective. Afterwards, life continues in skin and bones, perhaps with real friends and real relatives. The metaphor of a veil, the veil of writing, indicates that literature will open a way to deal with certain paradoxes and points to the distance required by reflection. At the same time, it stresses the urgent need for a closer understanding of patients and people overwhelmed by health problems. We can reason about them "as if" stories were real situations, a kind of simulation, only for approaching actual problems from other perspectives. General information about the disease or about some patients is of course available, and especially today because people are more aware of the impact of the disease and of its increasing presence in ageing societies across the world.

Discussing and learning bioethics would always require a case approach, but with certain limitations. In fact, bioethical analysis requires more than standard information in order to refine the arguments about the hard issues that concern patients, caregivers, and professionals. Thus, how can one achieve a subtle practical analysis without specific information? Here the argument in favour of literature in practical deliberation proposes a complementary methodology to analyze cases where information is restricted or does not exist. In this sense, the cognitive approach values indirect information and hypothetical cases. It could include simulation, since this has been considered an effective tool for training and education (Flechsig, 1983), without taking unnecessary risks. Of course, there are different arguments and approaches to the matter. For example, stories and fictional writing help to make people more aware of the situation of patients and professionals, improving empathy or making room for emotions (Nussbaum, 1988). Literature and narrative in general - including films (Casado, 2009, pp. 39-57) -, would help experts and non-experts to discuss complex bioethical questions such as health care at the end of life and the different dimensions of autonomy (Casado, 2014).

To sum up; here the cognitive version about the role of literature in bioethics ponders some of the outcomes of the use of indirect information. It does not undermine the central role that empirical evidence always plays in clinical practice and biomedical research. Through hypothetical cases, it is about possibilities for a better understanding of pain and illness and for a more in-depth reflection about real situations and real patients, caregivers, and professionals. Since the protagonists are usually under the flood of the disease, actual stories of dementia are quite exceptional, in every sense. When the information is accessible, only authorized people will use it for specific purposes and under specific conditions. National legislations will define these conditions and how to protect, and also how to disclose relevant data. Thus, talking and writing about cases have some limitations. For instance, everyone can discuss the case of Iris Murdoch because J. Bayley decided to write his wife's story. D. Friel MacGowin kept a first diary and published the book about how much her situation, relationships, and feelings changed after the diagnosis had been given: she had Alzheimer's disease. For years, R. Taylor has been very active, talking, writing, preparing a web site, sending pictures, and discussing his own situation with professionals, because he liked to help others with the same problem, Alzheimer's disease. On the one hand, non-experts and people still in training could have a legitimate interest in this kind of private information; on the other, respect for rights, duties, and the general protection of data must be the general rule.

For this, experts with access to these data may use them only for specific purposes, but the situation is different for non-experts or for people not involved with patients. How should they discuss relevant cases in public forums? Currently the dilemma is more feigned than real, because some priorities are, or at least should be, very clear as regards the protection of rights. In this context, literature opens an additional path to eluding the possible collision between duties, such as confidentiality, and opens deliberation about health problems and health and research policies. Thus, in practical deliberation the veil of writing could make some sense of difficult issues – such as how illness and dementia exert their awesome power over people – and hence supplement standard methods and resources for bioethical analysis. Narrative in general, and in different formats, would expand this methodology, but literature imposes an additional distance between reality and possibilities. According to Plato's classical definition, thinking is the silent dialogue with oneself (“inward dialogue carried on by the mind with itself without spoken sound”, Sophist, 263e). Literary texts could be part of practical deliberation in bioethics, especially when direct information is not available. Cases of dementia, and specifically Alzheimer's disease, exemplify the problems involved in obtaining complete information. The arguments to endorse this cognitive approach of the role of literature in the field could run as follows: communication about illness and pain could be limited; practical deliberation usually has a complex dynamic, and the use of personal data should be regulated and restricted to specific uses and people.

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