The Primacy of Autonomy in My Life Without Me (2002): An Example of Methodology for Medical Ethics

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Summary

This article proposes the film My Life without Me as being representative of the increasing importance of the autonomy of terminally ill patients in today’s society at the start of the third millennium. After discussing the basic moral conflict underlying the story, we sketch the contribution of bioethics to the configuration of an autonomist alternative to the traditional paternalistic model in the physician-patient relationship, using the work of Diego Gracia as a reference to clinical ethics in Spanish. To go further into the moral deliberation about the end of people’s lives, we address a version of the methodology proposed in 2001 by that author for the analysis of cases in bioethics, using cinematic narrative as a particularly rich and versatile material with which to work.

Keywords: Autonomy, Methodology, Bioethics, Deliberation.

Technical details

Title: My Life without Me
Original Title: My Life Without Me
Country: Spain and Canada
Year: 2003
Director: Isabel Coixet
Music: Alfonso Vilallonga
Screenwriter: Isabel Coixet, based on the story Pretending the Bed is a Raft by Nanci Kincaid.
Color: Color
Runtime: 106 minutes
Genre: Drama, Romantic
Production Companies: El Deseo S.A., Milestones Productions Inc., My Life Productions Inc. and SLU
Synopsis: Ann is 23, has two children, a husband who is usually out of work, a mother who hates everyone, a father who has been behind bars for 10 years, and a job as a night cleaner in a University she will never be able to attend during the daytime…. She lives in a caravan in her mother’s garden, just outside Vancouver. This grey existence changes all of a sudden after a medical exam. Paradoxically, it is from that day onwards that Ann discovers the joys of being alive.

With cinema, the teaching of medicine has a very useful tool for the study of ethical conflicts at the end of life. In his book entitled Acortar la muerte sin acortar la vida (Shortening death without shortening life), Dr. Juan Antonio Garrido states about My Life without Me that the more autonomous and the more accompanied death is, the more humane it becomes, and he proposes this film as an example to explore the people’s right to know the prognosis of their health problems, to give them the chance to exert control over the end of their lives; of being the main character in the process.

The Spanish-Canadian film My Life without Me (2003), written and directed by Isabel Coixet, stars...
Sarah Polley. This actress (and more recently, director) plays Ann, a young woman whose modest existence changes radically when her doctor tells her she only has two months of life left (Figure 1). As we see from the synopsis of the film above, Ann is 23, has two children and a husband who is a layabout, a mother who is everybody’s enemy, a father who has been in prison for 10 years, a job as a night cleaner at a University, where she will never be able to go…, and a galloping ovarian cancer.

My Life without Me. Presentation

Ann lives in a caravan in her mother’s garden, outside Vancouver, together with Don, her husband (Scott Speedman), and her daughters Penny (Jessica Amlee), who is six, and Patsy (Kenya Jo Kennedy), aged four (Figure 2). She does not get on very well with her mother (Deborah Harry), whom she travels to work with. At work, she only has one friend: Laurie (Amanda Plummer), but even then they don’t speak much because Ann uses headphones to listen to radio shows while she’s working (this is in the Spanish version; in the original we hear a broadcasted course on Chinese).

When Dr. Thompson (Julian Richings) tells Ann that she only has a maximum of 3 months to live, she refuses treatment because she wants to control what little life is left to her (in particular the memory she will leave to her children), so she negotiates with the physician about the control of her symptoms and makes him an accomplice in her plan: not to tell anybody so as to be able to tidy up matters pending.

Meanwhile, life goes on: when the grandmother tells her grandchildren the plot of a very nice story; about a mother who has a bad time, Ann gets mad at her because the story looks suspiciously like her own, and she forbids her mother to tell romantic stories to her daughters (only at the end, when she is trying to reconcile herself with her mother, does Ann lift the ban).

The writer Elvira Lindo does not feel that this film, located and filmed in Canada, could be credible in the Latin world: too communicative to serve as a landscape for that drama; in the interview in the DVD, the director herself recognises that if she were diagnosed with cancer she would tell everybody about it. However, the verisimilitude of the plot is enhanced by Ann’s night-time job, which places her in a strange world where she can lie and skive off work without anybody realising it, so she is able to put her plan into operation.

My Life without Me is one of the purest cinematographic expressions of patient autonomy. In this film, the healthcare relationship could be encompassed within what has been called the “the patient autonomy model”4, in which we see a primacy of the patient’s wishes and at the same time the risk that physicians might not be able to exert their responsibility towards their patients. Ann must take all the decisions.

The film is completely imbued with Ann’s perspective: she appears in all the scenes, often within the setting of a monologue. In the initial sequence, Ann’s voice is heard in off talking to herself, and of course to the audience, and she tells us with a sweet but firm voice “This is you” (Figure 3). But this second person she invokes—that “you” from where the narrator exerts her autonomy—is split by a new event. Her ego has become someone else: before, she wasn’t one of those people who enjoy looking at the moon, who spend hours watching the waves or the sunset, or the wind in the willows; but who would have thought; something has changed and that I has become a you that must be directed and addressed. Ann makes the rules for herself; she becomes autonomous. However, this is not easy. Being autonomous requires deliberation, decisions
about different alternatives, and she is not used to thinking because she has never had much free time to do so. Her life has always been governed by others.

The principles of bioethics

Ann spends her time in the film doing what she has been unable to before: namely, to deliberate. And if there is a word that can summarise the Spanish contribution to international bioethics, then that word is “deliberation”, as has been proposed by Diego Gracia, Professor of History of Medicine at the Complutense University in Madrid.

Although bioethics covers a broader field than medical ethics, the two terms are often used interchangeably. As is known, in 1979 the first edition of The Principles of Biomedical Ethics (Figure 4) unleashed in the recently configured discipline of bioethics the four principles of respect for autonomy, non-maleficence, beneficence and justice. These principles immediately became very popular, to the point where they became known as the “Georgetown Mantra”, referring to their University of origin. Today the book is in its fifth edition and continues to be a classic; indeed, it is one of the most important manuals in the field.

Ten years after Beauchamp and Childress published their book, Gracia did the same with his Fundamentos de bioética (Fundaments of Bioethics); the book that implanted the approach of the four principles in Spanish bioethics (photo 5). Gracia read The Principles of Biomedical Ethics in the light of Aristoteles, Immanuel Kant and Xavier Zubiri, but assuming that, alone, such ethical theories were too abstract to address the ethical problems of medicine and the other life sciences. In order to establish the duty of some agent in situations of conflicting obligations, a process of moral deliberation is required. Gracia proposes deliberation as a method by which we can explore our considered judgements or moral intuitions and contrast them with the principles of bioethics, and with its foreseeable results or consequences.

Today, it can be said that bioethics in the Spanish language has come of age: proof of this is that Gracia’s Fundamentos de bioética has been reprinted 18 years after its first publication. As stated in the prologue to this second edition, dialogue with the classics hardly ever disappoints. For many readers in Spain, in Europe, or in America, this already classic book has underpinned an edifice built around a methodological proposal based on the principles of non-maleficence, beneficence, autonomy and justice.

This methodological proposal, which has been very influential in most public health institutions in Spain and Latin-American countries, includes one principle that demands respect for the autonomy of the patient by revealing the pertinent information and fostering freely made decision-making, together with the principle of non-maleficence, which defends the obligation of not inflicting harm. Additionally, the
principle of beneficence demands that professionals should adopt active measures to help their patients, balancing the possible benefits of an action against its possible costs or potential harmful effects. Regarding the principle of justice, it demands equity in access to research and medical treatments and, in general, in the distribution of the resources of the health services.

**My Life without Me: Commentary**

*My Life Without Me* contains an extreme argument for the priority of patient autonomy, in opposition to one of the initial features of Gracia’s theory, which gives less normative force to the principles of autonomy and beneficence than to the principles of nonmaleficence and justice. For Gracia, the latter couple belong to a minimal ethics that is publicly compulsory, while compliance with the former is a matter of private excellence. This position has been challenged by Pablo Simón, who argues that respect for autonomy is not a principle as the other three, but rather a new perspective over them, which includes autonomy-promoting duties of nonmaleficence, justice, and beneficence⁷.

The film suggests something similar: in the new list of bioethical priorities respect for autonomy is fundamental. This is especially the case in palliative care; those active treatment programs aimed at maintaining or improving the quality of life of patients like Ann, whose illnesses no longer respond to cures. The aim of palliative treatment is to control not only the pain and other unpleasant symptoms (Figure 6) but also suffering, understood in a more holistic way; to help patients to live the fullest lives possible in their last months or days and to offer them a “good” death, or at least a dignified one. When therapy gives way to palliative treatments aimed at providing a decent death, certain traditional principles lose their normative force for the benefit of autonomy (and in other situations, autonomy loses that privilege, as for example in emergency medicine), since it is in those difficult moments that the patient most needs to maintain a certain feeling of his or her own worth as a human being and a certain feeling of control over the process of death. Although the correctness of her decision may be debatable, Ann chooses to lie to her family because for her this is the only way to satisfy those two needs.

Nevertheless, this exercise of autonomy is not at loggerheads with beneficence for others (in her final message to her daughters, she tries to transmit self confidence in them as autonomous beings: *you must trust yourself, trust your ability to do things, to forge ahead*), although leaving the spectator with serious doubts; we may well ask ourselves whether the daughters have the moral right or not to say farewell to their mother. The obsession for autonomy may even become irresponsible, as in wanting to control all aspects of life, at least when, upon exercising it, the patient ignores or overrides the desires of others. However, it is also true that a certain dose of self-control is an integral part of western society, and that European and American health authorities seek to foster the responsible making
of decisions concerning the last part of someone’s life, for example, via “living wills”.

Ann wants to be remembered and to control those memories through her “living will”, which she leaves on tape in the hands of Dr. Thompson (Figure 7). In one scene, which was not included in the final cut, Ann sleeps with a stranger she has met in a bar; he asks her name and she says that she is not going to tell him; I don’t want you to forget it (in another scene that was also not included, she writes a list of the clothes she wants to be dressed in at her funeral). This determination to control her legacy leads her to ask Dr. Thompson to renounce the therapeutic ends of medicine, keeping her on palliative care. I don’t want any more tests if they aren’t going to save me, says Ann. I don’t want to be here; I don’t want to die here; I don’t want that all my daughters will remember about me is a hospital room. I prefer, I prefer for once, to do it my way… The physician accepts the deal as part of the therapy (that of Ann, but also of him as a physician with problems of relationships with his patients), as long as she will accept something to mitigate the pain (Figure 8).

Nobody, except Ann, thinks about dying in a supermarket. Today, death is an increasingly invisible phenomenon in the public sphere (even when it erupts obscenely or trivially in our lives, perhaps as a result of that same process of marginality). Despite this, there are cultural differences with regard to the end of a person’s life and of communication in this stage. An ethnographic study has shown that among North American citizens those of European and African origin tend to see the disclosure of a diagnosis as something that empowers a person and allows him/her to make decisions, whereas those of Mexican and Korean origin tend to see it as something cruel and even harmful for patients.

Ann evidently belongs to the first group since for her to control the disclosure of the diagnos-
A method for clinical ethics

To facilitate the exercise of deliberation, Gracia\(^1\) has proposed a deliberative method that attempts to analyse ethical problems in all their complexity, pondering the factors that are involved in a specific action or situation with a view to seeking the optimum solution, or if this is not possible, the solution that is most prudent or least harmful.

In fact, this method is used in the Ethics Committees of many health institutions in Spain to help structure the deliberation and control the feelings of fear and anxiety in situations of conflict. According to Gracia, deliberation demands careful listening, vigorous efforts to understand the situation in hand, analysis of the values involved, discussion of the possible and best courses of action, clarification of the legal framework, and counselling. All this is integrated in an eight-step model:

1. Presentation of the case by the person responsible for decision-making.
2. Discussion of the medical aspects of the situation.
3. Identification of the moral problems.
4. Choice, by the person responsible for the case, of the moral problem in hand that needs to be discussed.
5. Identification of possible courses of action.
6. Deliberation about the best course of action.
7. Final decision.
8. Discussion of the decision, and discussion about that discussion, which we should be prepared to defend publicly.

The most conflictive point of the process is the sixth one, when after identifying all the possible courses of action the moment arrives to make a moral judgement—to choose the best one—which is sometimes not at all simple. Gracia\(^2\) has proposed analysing each course of action in four phases: in the first, the ethical principle of equal consideration is invoked; in the second, each course of action is contrasted with the principles at play, and in the third with the foreseeable consequences; in the fourth the moral judgement is made. Schematically, then, one would have something along the lines of the following.

I. The moral reference system.

II. The deontological moment of the moral judgement.
   a. Level 1: Principles of non-maleficence and justice.
   b. Level 2: Principles of autonomy and beneficence.

III. The teleological moment of the moral judgement.
   a. Evaluation of the objective consequences, or of level 1.
   b. Evaluation of the subjective consequences, or of level 2.

IV. The moral judgement.
   a. Contrast of the case with the “rule” as expressed in point II.
   b. Evaluation of the consequences of the act, to see whether an “exception” to the rule might be required, in agreement with point III.
   c. Contrast with the decision made with the reference system (point I).
   d. Final decision.

The “reference system” that Gracia refers to considers that the principles of bioethics, and the moral judgements into which they materialise, are formally preceded by a framework whose content could be summarised thus: *All people have dignity and deserve equal consideration and respect.* This system, which for Gracia is both the starting point and the touchstone of healthcare ethics, is not new: one of its most complete expressions can be found in Kant, and it forms part of the moral landscape of all modern societies.

Presented thus, the method may appear somewhat abstract and difficult to grasp. With the dual aim of illustrating this method for the analysis of cases of bioethics, on one hand, and to go deeper into deliberation about the end of life, on the other, we shall now try to deliberate about *My Life without Me* using Gracia’s method. We can take the first step, the “presentation of the case” as a given since we did this at the beginning of this article. So let us follow on with the sequence outlined above.

Discussion of the medical aspects

After feeling nausea, giddy and sick, Ann goes to the hospital (she thinks she is pregnant), but they find a tumour in both ovaries, with metastasis to...
her intestines and liver; that is, we are dealing with a phase IV cancer (Figure 10) and [as said in the film *Wit* (2001), by Mike Nichols] *there is no phase V*. The prognosis is at best of two or three months.

This class of cancer usually has a very poor prognosis because the symptoms are vague and fairly non-specific, such that it could well be overlooked until the final phases. Neither is it possible to ascribe it any specific cause, unlike cervical cancer, which in more than 70% of cases is caused by human papilloma virus (HPV), and for which a vaccine is currently available.

In the film, we are not told about what Ann’s evolution will be like, but it is not very realistic to believe that she would be able to cope with the situation alone just with the aid of a few analgesics.

**Identification of the moral problems**

Without being exhaustive, the following are some questions that tend to arise after one has seen the film:

1. Is Dr. Thompson a good physician? Is it correct to give bad news in the way he does? Can he thus accept Ann’s refusal of treatment?

2. Should Ann tell her family and friends? And the physician; should he?

3. Is Ann right in looking for a neighbour (the nurse played by Leonor Watling) to replace her as wife and mother when she is dead?

4. Did the nurse act correctly in the case of the Siamese twins that she tells Ann about when they meet?

**Choice of a moral problem**

Problems 1, 3 and 4 are not simple, although in all three we may assume an affirmative answer. Dr. Thompson has communications problems, especially when attempting to give bad news, but in his relationship with Ann he shows technical capacity and compassion; assuming that Ann can indeed cope alone he cannot oblige her to follow a useless therapy that, moreover, she does not want. With respect to Ann, that she should decide to proceed with her family as she does may seem to reflect an unrealistic or even manipulative attitude, but it could also be understood as a peculiar expression of anticipated wills, something perfectly valid today in healthcare relations. Regarding the actions of the nurse, and overlooking the artificial nature of the case posited (Siamese twins cannot be of different sex, as stated in the script), the nurse accompanies her small patients with exemplary dedication to palliative care, even at the risk of “burning out” (and, in fact, the incident does lead her to abandon obstetrics in favour of geriatrics).

Problem 2, however, does not admit an affirmative answer so easily, and that is why we shall choose it for analysis. It is true that Ann forbids the doctor to speak with her family and that without her authorisation he cannot break the physician-patient confidentiality by informing third parties (things would be different if we were dealing with a problem of public health; if, for example, we were in a situation of a cancer caused by HPV with risk of sexual transmission, since Ann has relations with at least two different people. However, this is not the case). In the film, Ann keeps quiet right up to the end. Regardless of how feasible it might be in the real world, to what extent can she keep the secret of her condition as a terminal patient? Does she in fact have any obligation to communicate the diagnosis to her husband, her daughters, her friends or her lover?

**Identification of the possible courses of action**

Focusing on the problem of Ann’s obligation to reveal her situation, among other options Ann has the following:

1. Disclose the diagnosis and the prognosis to her family and loved ones.

2. Reveal only the diagnosis, so that they can start getting prepared.

3. Keep quiet about both the diagnosis and the prognosis (this is the option she chooses in the film).

4. Delay all decisions until she has the biopsy results and perhaps a second opinion.
Deliberation about the best course of action

In practice, Gracia tells us, the assessment of each course of action can be done in two steps, or “moments”. In the first, the “deontological moment”, we make a contrast of each course of action with the principles of bioethics, identifying the possible moral conflicts.

In turn, this first moment can be divided into two levels. In the first, we attend to the “level 1” principles: non-maleficence and justice: for Gracia, the principles of this level “determine our duties towards all other human beings, both as regards the order of their biological life (the principle of non-maleficence) and in that of their social life (the principle of justice)”. In her decision, Ann must avoid harming others and must give them what is their due. This seems to be her intention: minimise the negative effects of her death on the family and take maximum advantage of the time that remains to her [Le temps qui reste (2005), to say it with the title of a film by François Ozon, who addresses a similar issue (Figure 11)]. She must also avoid hurting herself, but since suicide does not enter her plans, there seems to be no greater conflict here.

In “level 2” of the deontological moment, we encounter the principles of autonomy and beneficence. Both principles, following Gracia, delimit “the private space of each person, which this person can and must manage according to his/her own beliefs and ideals in life”. It may seem that the principle of respect for autonomy would recommend any course of action from among those proposed, as long as they are chosen with authenticity; but the fact is that Ann chooses 3. Also, she does so because, together with 4, it allows her the possibility of continuing in the world of the (apparently) healthy, thus gaining time to carry through her plans. Regarding beneficence, this principle leads Dr. Thompson to respect Ann’s option (Figure 12); in turn, she will act beneficently if she chooses an option that is coherent with the conception of good in her immediate social surroundings. In this regard, it seems that her relatives above all value being able to be with her: her husband, Don, speaks about the possibility of having another picnic on the beach, and her daughters are thrilled when she accompanies them to school. In this sense, the choice of not telling about the diagnosis becomes a little white lie resting not only on the respect for autonomy but also on the principle of beneficence (curiously, Don does not know how to lie, and in the film this disqualifies him as a moral representative of Ann, who is a true expert in telling stories to her children and lies to her mother). This beneficent intent of Ann is also especially visible in her relationship with Lee (Mark Ruffalo) (Figure 13), whom she rescues from depression, something that would not have been possible either if she had not transiently saved her small plot of personal autonomy through option 3.

The second moment, the “teleological” moment, is the time for assessing the circumstances that run together in the particular case and the foreseeable consequences of each decision, asking our-
To assess the objective, or level 1, consequences, we must begin with the fact that Ann's illness is presented to her (and to us) as incurable and uncontrollable; whatever she does, she will die in a few months. The consequences of the proposed courses of action will not change that fact in any case. One must therefore try to discern the consequences of her acts on others, in particular the members of her family. On revealing the diagnosis, the courses of action 1 and 2 might lead to a series of disturbances in the family; it is difficult to know how Ann's daughters will react to the news of the imminent death of their mother and neither can we say that her husband is a model of maturity and restraint: as a father and husband, the film portrays him as good-natured and kind, but also as someone rather naïve and impulsive. In contrast, options 3 and 4 (no communication at all, or a delay in communication) will not have immediate effects, although it is possible that these courses of action might act as a sort of discrimination against the daughters and Don, which could be unjust if there were a moral right to know the truth about the medical status of our relatives. This could be so in the case of relatives in our charge (a progenitor has the right and indeed the duty to know the medical status of his/her under-age children), but the case in hand is precisely the opposite. Furthermore, we are not addressing an infectious disease, or one of mandatory disclosure, such as tuberculosis.

When assessing the subjective, or level 2 consequences we must take into account that, at least at the beginning, the principles recommend the option taken by Ann: in fact, in a similar case Gracia\(^6\) defends the right to autonomy of a patient who does not authorise his doctor to disclose the diagnosis to his family and refuses futile treatment. Having accepted this, the subjective consequences may play a role in the evaluation of courses of action 3 and 4. To choose this latter and thus resuming the medical tests (biopsy) might give Ann greater certainty as regards her status, but at the cost of losing time and energy in visits to the hospital and increasing the risk of her family finding out about her condition. If Ann has faith in Dr. Thompson's competence, and accepts the palliative route, then there is no sense in continuing with the therapeutic strategy. For this reason, she rejects a second opinion, since what she needs is not more tests but more time: time to think and time to take advantage of the time left to her.

Finally, it is time to emit a moral judgement about the best course of action and, therefore, about Ann's behaviour. To do so, Gracia\(^11\) proposes an ethics of responsibility that seeks to act in accordance with the moral principles, but admits exceptions that can be justified by virtue of the consequences “as long as we have reason to believe that the application of a norm or principle will be detrimental to a person's dignity”. If we contrast the case against the rule, it would appear that Ann's decision, with her choice of option 3, is guided by the principle of respect for autonomy and the duty of confidentiality with respect to medical data; both recommend accepting the decisions of the patient about how, when, and whom to tell about the diagnosis and prognosis. If we assess the consequences of the act, to see whether it is necessary to make an exception, it seems that Ann's decision does not involve a lessening of the other principles; since the truth about her condition will inevitably be revealed, all courses of action imply certain damaging effects against Ann's family, but gaining a bit more time may elicit beneficial effects both with respect to Ann's self-esteem and in her relationships with her loved ones. In so far that there is no maleficence (or there is no maleficence in comparison with the other options) and no injustice is committed, it is not possible to justify an exception to the principle of respect for autonomy. And, with respect to contrasting the decision made with the reference system, all the characters in the film behave with an attitude of dignity and respect towards others.

**Final decision**

In the case addressed in *My Life without Me*, Ann does well in not telling about her diagnosis and prognosis for the time being. She cannot prevent her
imminent death, nor the affliction that this will bring to her social circle, but her decision does allow her to act in an autonomous and beneficent fashion, without compromising the principles of justice or non-maleficence.

Additional arguments pro and contra

We are addressing a case of weak or justifiable paternalism, above all if we consider Ann’s daughters. It is not so clear that Ann can be paternalistic with respect to her husband or mother, but in this case, she is the patient—not the others—and it is her own wellbeing that must be taken into account first. Ann is the true heroine of this film, the only one who realises that all the shining shop windows, as we hear in the film, try to draw us away from death.

References

3.- Coixet I. Mi vida sin mi / My life without me. Madrid: Ocho y Medio; 2003. p. 10.

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