

## Care production in health team focused on living work: the existence of life on death territory

Magda de Souza Chagas(a)

Ana Lúcia Abrahão(b)

(a) Departamento de Saúde e Sociedade , Universidade Federal Fluminense. Rua Marquês do Paraná, 303, 3º andar, Prédio Anexo ao HUAP, Centro. Niterói, RJ, Brasil. 24033-900. magdaschagas@ gmail.com

(b) Departamento de Enfermagem Médico-Cirúrgico, Universidade Federal Fluminense, Niterói. Rio de Janeiro, RJ, Brasil. abrahao@vm.uff.br

Death and life are dimensions involved in the process of health work and are crossed by the way society relates to diseases, patients and outcomes of this process. In this paper, we set out a qualitative research with a team of palliative care, in order to debate: why the health work process produces ways to prevent, camouflage and disregard something that follows the existence, i.e. death? Does death bring us nothing but pain and feeling of vulnerability and finitude? We build arguments that articulate the live work in action with death in the work process in health thus concluding that the professionals who participated in the study used live work in action based on a complex and dense space of living life even in the face of the death.

*Keywords:* Death. Patient-centered care. Attitude regarding death. Palliative care. Live work in action.

### Introduction

Birth and death are issues involved within health work process and hospitals are their privileged setting. However from the eighteenth century on, this place previously intended for the care of the poor, became a place to be born and to die assisted under the presence of clinical knowledge and discipline<sup>1</sup>.

This hospital-oriented movement has profoundly impacted the way society views and relates to the disease, the patient, and the outcome of this process. Even if in ancient times there was some autonomy of the families in treating a patient, their pains and their possible death, from the moment the medicalization entered scene, the relation of dependence began to be established, and has consolidated its predominance to the present days.

The way society has come to recognize death has a close relationship with the space where it happens, the hospital space. In this way, Kóvacs<sup>2</sup> points out that "Western society insists on the accidental character of death: accidents, illnesses infections and advanced old age" in a way that death is stripped out of its characteristic of necessity as a vital process. Our society does not know what to do with the dead, with these strange bodies that have stopped producing and what should be seen as natural becomes clandestine and thrown to the bottom of consciousness. Something that is also present in the way that health work operates in hospitals, isolating the process of dying, cloaked in the silence of hospital wards.

Elias<sup>3</sup> considers that it is not death, but the knowledge of death that creates problems for humans. For this author, death is one of the great biosocial problems in human existence as it is pushed further and further into the backstage of social life. On the other hand, there is an ambiguity made explicit by the flight, the willingness to forget but at the same time an attraction in the daily news, TV, newspapers, films, notwithstanding the daily death in the streets that repeatedly attracts the proximity of "curious people". Morin<sup>4</sup> speaks of the duality that the human being experiences in relation to death when confronted with the awareness of the fact of death and the belief in immortality, coming from the affirmation of individuality. "Pain caused by death only

exists if the individuality of the dead is present and recognized: the more the dead are close, intimate, familiar, loved, respected, more violent is pain"<sup>4</sup> (p. 32).

For more negative reactions people may have with death, it keeps its presence in the reflections and, may we say, in the search for meaning in life. When talking about death, attention is needed<sup>2</sup>, since there is the final death of life, but also the many deaths that we will experience in the evolutionary process (partial or total deaths in the somatic, mental and social areas, losses, separations, changes, a child leaving home, etc.). Or even what the experience with death and dying leaves impregnated in each of us, responsible for our interpretation and experiences with the other deaths.

The issues above are related to the way we choose to live or not to live the process of dying. When we turn our attention more closely to the health services, these questions are accompanied by the current conjuncture of society, how the mode of production for capital accumulation is dependent on technological innovations, which are incorporated daily into the actions of care in the field of health. In this sense, health work, despite not having the characteristics of industrial work, has always been impacted and influenced by hegemonic productive organizations in the context of capitalist organization. According to Pires<sup>5</sup>, even it presents a few "handcrafted" instances, health work is already compartmentalized, and this refers to the "slicing of the user", in acts of dissection and cleavage of care, separating life and death in the work process in health.

In the development of daily activities in the world of work, the health worker can exert leading roles/freedom or leading roles/reproduction, translated in this process as living work or dead work respectively. Approaching this intense action we can perceive the "(...) moment of work itself expresses exclusively the living work in act. This moment is marked by the full possibility of the worker acting in the productive act, with the maximum degree of freedom"<sup>6</sup> (p. 45).

Working on live work in action<sup>7</sup> is precisely work at the exact moment of its execution, the production of care, a process of intense use of technologies. Technologies of different types interact in the way of producing care. Depending on the ways and

modalities of the use of technologies, the work process is more or less creative, focused on interpersonal relations, bound to norms and protocols or guided by the logic of machines. In this case, it is possible to recognize three types of technologies<sup>7</sup> within health work: light; light-hard and hard, corresponding to interpersonal relations, standards and equipment, respectively.

We can postulate that the living work exerts the leading role in the work process in the field of health, gaining different forms according to the needs of the users and the practitioners” supply, an intense movement that accompanies birth and death.

Thus, two questions are present in the elaboration of this article: Why, in the health work process, do we produce ways to avoid, camouflage and disregard something that accompanies us and will eternally be present, i.e. the existence of death? Does death bring us nothing but pain and feelings of vulnerability and finitude?

## **Methodology**

In the provocative attempt to construct arguments to the questions raised in this article, we proposed a methodological path articulating living work in act and death, using as guideline the qualitative research of the descriptive type. We started to explore the database, from November 2015 to January 2016, of the national survey *Implantation of home care under SUS – modeling from current experiences*<sup>8</sup>, completed in the year 2008.

The design of this study is guided by the qualitative research, as it supports the assumption that societies are made up of micro processes, in which reality is not configured as a massive block, but "A multiplicity of social processes that act simultaneously, in differentiated temporality, composing indeed a totality"<sup>9</sup>. In this sense, the proposal to investigate – “Why, in the process of health work, do we produce ways to avoid, camouflage and disregard what accompanies us and will eternally be with us, i.e. the existence of death?” and “Does death bring us nothing but pain and feelings of vulnerability and finitude?” seems to be appropriate the use of qualitative approaches,

because they allow to explore the reality from the starting point of a process with its multiplicities and several compositions.

We opted for the descriptive design, because it allows the exposition with exactness of the facts and the phenomena of a certain reality, being able to establish relations between the variables<sup>9</sup> and in this process to be able to construct arguments that articulate the living work in act with the death within the work process in health.

The study participants were interdisciplinary-trained health professionals, users / patients and family members of a Palliative Care (CP) service linked to home care. In this article we will approach the perspective of health professionals. Their participation was accepted by reading and signing the informed consent term, according to Resolution n° 196/96 of the National Health Council. The survey was approved with the number 233/05 of the Ethics in Research Committee, The anonymity of the participants was guaranteed and the inclusion criteria of the professionals were: individuals who worked for more than 01 (one) year and participated in the activity of attending to users/patients and family members. All participants volunteered for the study.

The techniques of data collection used were participative observation and interview. In the former the researchers are guided by the employment of all the senses to examine the event in its context and describe it. This technique implies the need for the researcher to be at the same time distant and close regarding the questions under study. In this process it was confirmed that the idea of neutrality of the researcher is outdated. What we need is to construct mechanisms to evaluate the effects and implications of the researcher in the field. The record of data coming from participative observation was carried out using a field diary.

The interviews were conducted as informal conversations about the work process of the health professional facing death, they were carried out in the workplaces of the participants, recorded with the aid of an mp3 player recorder and transcribed in full. The researcher defined the approach with the participants of the research.

The material collected and stored in the research database allowed to define more clearly the work process articulated to live work in act and death. This material was analyzed and correlated with the records of the participative observation, with emphasis on the reactions, expressions and dynamics of the professionals observed and confronting the interview that was transcribed. To ensure the privacy and anonymity of those involved in the research, fictional names were created for professionals whose excerpts are presented below.

The analysis was carried out using the Thematic Content Analysis. The phases of conducting the Content Analysis adopted for this study were: a) The transcription of the interviews that constitute "the corpus of the research and that was submitted to the analytical procedures"<sup>11</sup> (p. 122); b) The floating and globalized reading of the data – annotations of the field diary and interview; c) The exploration of the material by means of codification, was carried out by "cutting the text into its parts, to be categorized and classified in order to decode the meaning of the parts related to the whole, allowing a representation of the content or its expression"<sup>10</sup> (p. 129). Next, by categorization – which is a category classification operation, bringing together a group of registration units under a generic title– the grouping was done using the common characteristics of these elements<sup>11</sup>. In this study, we used the semantic criterion of categorization, i.e. the meanings. The treatment of the results obtained and the interpretation were processed according to the issues established and in dialogue with the existing literature. After interpretation, the convergent or divergent lines were identified, similar or contradictory results and the analysis was carried out<sup>12</sup> based on these evidences. This process entailed the creation of two categories: "Death under Care" and "Is There Life Working with Death (?)", which allowed us to explore the multiplicity of processes of living work in act and

death that act simultaneously, in different temporalities, thus composing the totality of care in health.

## **Results/discussion**

The analysis of the data explored the content of the interviews and the daily result of the observations that were contained in the research database, and are presented below in two categories.

### **Death under Care**

This category has a strong relation to the idea that death, even present in people's lives, has been "kept" in hospitals along the development of societies, especially in Western societies. This process takes us back to the discussion of the dying process and the place of death.

The analysis of the field diary (participative observation) shows the construction of a new space in the production of care, from "live work in act", built by CP teams, of the service studied either in services that work directly with death and the dying process, This new space externalizes the complex possibility of interpersonal relationship among health care professionals, caregivers and patients.

The professionals are themselves facing finitude, experience and care for people at the moment and at the still feared by humanity process, death<sup>13</sup>. In this process they unexpectedly express life, experiences, bets, desires, sufferings being them from the professionals themselves and from others. This can be seen in the excerpts below and in those that will appear in the body of this text.

“ [...] Today I think much more of my death than I had thought before. I am afraid of suffering, today it is clear to me what death is ... But I know how to separate

death and suffering, and I am afraid of suffering”. (Highlight of speech of the health worker – João)

“ [...] I know I like my service I like to help people, and I do not like to see anyone suffering! I do not think anybody likes it! So I think that every time a patient needs me, I feel good about my service and I do it very well because he does not need to go to the hospital”. (Highlight of speech of the worker of the health – Pedro)

A two-way street is created and experienced with builders not noticing themselves as builders of the path in action, right there, at that moment with steps, bodies, all in movement. To be naked is something that happens among people who relate, some more and some less, as in everything in life. During the participative observation, it was possible to identify that users when being vulnerable, when undressing, provoke and make it possible for the professional to be naked too, to whatever degree and perhaps being the facilitator in a process of self-analysis as described in the excerpts from the interviews hereby highlighted.

“ [...] I went through several crises ... What do you do with feelings? First it is hard to take some feelings because there are some patients that generate anger !! I thought: me, angry at a patient!? What kind of professional I am !?! ... Because you have a patient that creates a ruckus, they are aggressive with you, everything you do is not good ... And you think they're going to get nicer? No way, it gets worse!! So there are patients that generate anger in you! It was hard to accept it! ... So, I accept people's feelings better today, right?! And I know how to circumvent the situation. If the patient generates a lot of sadness in me I really cry ... I allow myself to have feelings. I can not see a mother who has lost a child of 2 or 3 years crying on my side and I be, there ... Imagine, if it were me? I wanted to kill everyone if they did not want to kill me! So I allow myself, today, to have feelings, right?!” (Highlight of speech of the health worker – Mariana)



To Vasconcelos<sup>14</sup> health work faces complex, multi-dimensional problems and scientific knowledge has answers only to some aspects and reason is insufficient to deal with all its complexity. It also requires intuition, emotion and acuity of sensible perception. Considering that in order to take care of a person entirely, one must be present as a whole person; one must have developed and integrated the rational, sensory, affective and intuitive dimensions, without which the experience of vulnerability and pain of patients become oppressive and sufferable, forcing them to protect themselves with a set of defense mechanisms.

The palliative care modality makes it possible to review the involvement between the professional and the user, the involvement of which is spoken and often excluded from the care provided by the training schools. It is something that penetrates the therapeutic spaces, where the person who gets involved is often not seen as "professional", where other dimensions of care beyond technique are little valued by the health professionals themselves<sup>15</sup>.

Cassorla<sup>16</sup>, dealing with the need for accompaniment at the moment of "the passage to death" states: "technology, machines and concrete objects, fruits of our modern society, are not enough for humanity to live better. Human beings can not live without the help of other human beings in all vital circumstances, and especially in key moments like death.

Gleizer<sup>17</sup> writing about Spinoza, and human affectivity says that for that philosopher, "the human body is an extremely complex individual, composed of several bodies, each of which is also very composed. Thanks to this complexity, is able to affect and be affected in various ways by the outer bodies, being able to retain the affections, that is, modifications caused by these interactions. "

“ [...] So you live a lot inside the disease right?! Just learning to respect the time he did not want any more "Please do not do it anymore, now I want to die, as

long as you have saved me you are eliminating the possibility of my death." So when I heard this from someone, who was really prepared for death, right?! Then I thought it best not to do anything. (...) If I do not do well I just do not do, respecting the will of the patient, that this is right. In fact, what that patient wanted, for me, was that he wanted to die, that I let him die". (Health Worker – Shirley, excerpt from speech)

### **Is there life working with death (?)**

When analyzing the material of the database (interviews and field diary with the observations on the work of the team) it was observed that, as philosophy registers, seeing death and reflecting on death causes humans to be face to face with their own finitude, fragility, mortality. In this way, direct experience with the process of dying provokes on people who work directly with death, self-knowledge, to learn how to deal with images and stories filled with symbolisms that express in synthetic form their dilemmas, learning experiences, fears and desires present in the depth of the psyche .

This process will depend on the availability of each person, their decision to contact themselves and the "I" of the other, but if they decide to do so, if they decide to enter into a deeper dialogue with the patients, they will confront themselves daily with the human vulnerability and will have to deal with the duality imposed on them through the biomedical model. Breaking apart with this duality and experiencing the drama and human existence of those who are care for is a great challenge.<sup>7</sup>.

“ [...] Death, it is like this to me ... What we have been talking about ... Are you afraid of death? No, I'm not afraid of mine! I'm afraid for the people I like. So, that's the problem! As people say, "The CP people ... They're all happy when the patient dies. That is horrible! There everyone gets happy! "But people, the suffering is so great, so great that you really are relieved when the patient goes, dies! I pity the family. Of course! But when he dies! Thank God! Not for the work

he gave, but for the suffering as a human being. We try to reduce what we can, but this suffering of the loss of relatives, this relationship of the team ... We get very close, there is no way to do palliative care without approaching, without getting involved, without putting yourself in their place". (Highlight of speech of the health worker – Mariana)

The above statement highlights suffering with death not as something hidden, but an effective approximation of the worker with the dying process and the family. The place of suffering reverts to relief, a conscious alleviation that life, the process of living work in the act expands the possibilities of producing care.

" [...] I did not think about protecting myself (from contact with a patient), that's his problem. We also meet others there too. Because I think it's a friend I see. There I do not see a single patient. So much that friendship comes. So, do you try to defend yourself from a friend? It's a permanent contact". (Highlight of speech of the worker of the health – Pedro)

For Foucault, according to Ortega<sup>18</sup>, friendship is the sum of all the things through which one can obtain mutual pleasure, and the fact that friendship has been abandoned in modernity is due to the fact that it started to play sociopolitical tasks. However, the friendship that existed in antiquity was a kind of institutionalized relationship, which left no room for experimentation, as well as being used in coercion, task systems, and obligations. "The ethics of friendship points to the intensification of experimentation. Experimentation as an ethical foundation focuses on the perception and enhancement of both yours and your friend's pleasure". "Friendship represents a way out of the dilemma between a saturation of relationships arising from the dynamics of modernization and a threatening solitude" (p. 167).

The bond<sup>19</sup> between health professionals and users is seen as shaper and facilitator of care, since in this process it is possible to establish a co-responsibility

relationship on the therapeutic plan. It constitutes one way to operate and "work" the bond issue.

The bond, united to physical contact and touch, gains the dimension of humans in contact. It is not necessary to stop thinking about the bond as a shaper and facilitator of care in its "negative" aspect, if we can or should think dichotomically, but touch brings to bond a starter, remitting and close dimension. It is a light technology not always included in the therapeutic processes of caring. An affective bond that needs effective communication. For it to occur, in order for the bond to be established, the acceptance of the other as legitimate and bearer of autonomy is paramount.

" [...] You end up having physical contact right?! What is this thing of touching, touching the patient inevitably ends up turning to you a great pleasure and he ends up enveloping you. This patient, as far as you can, of course! As far as you can and it's allowed. But we end up getting too involved with him, I work a lot with this". (Speech from the health worker – Silvia)

Health professionals while working build bonds and friendship with users and family, they are in free use of light technology. Thus, it is possible to observe that palliative care workers are involved, operating very often with light technologies, and transiting easily in fields excluded by science. Those are the cases of spirituality, religion, touch, involvement, affectivity<sup>15</sup>.

" [...] It's been 10 years of profession. I've been all over the place and there's no comparison! When you're there on the side of a dying patient, the gratification is much greater. You take it, you know? That from him! You have an instant like this, the end. You know, when the human being becomes so open, so vulnerable that you can discover all of it. That's how he gets, he's vulnerable, he's a little bit of people. You know? With all defects, all the qualities. So you can get this from

him and you can learn a lot from this woman who has a problem, who is depressed". (Highlight of speech of the health worker – John)

The kind of work performed by professionals of the CP team, although using light-hard and hard technologies often differs from the day-to-day of so many other professionals. They rediscover new spaces and reinvent paths, in fact they do what we discuss and idealize in health care in their micro-spaces. As the user/patients' autonomy in the face of death, when accepting the right of the person to participate and/or direct their process of care, the professionals are once again faced with something that is unfolding and thus seek answers to unprepared questions.

The difficulty of witnessing the first death and perceiving the need to respect not only the patient's will, but also to recognize the limits of your own professional activity, was reported by one of the professionals. The difficulty of letting die, of knowing that the use of a technique, a procedure, would prevent death from happening, but instead respecting the patient's request and let him/her go, in direct confrontation with the omnipotence the practitioners think they have in their hands. It is the omnipotence of giving life or leading to death.

" [...] But before that I had a certain resistance with regard to letting die. I joined the CP 2 years ago I think. It took me two years to understand that not every patient can do anything ... That my personal characteristic of wanting to save everyone ended up modifying itself, because I had a need, that was such a difficult thing for me, Not to inhale a patient, not to do something while he was still there needing me, you know? (...) I fought a lot with my conscience, with my spirituality with my professionalism, this way of being, to be able to fight against that. Today I let die, if I need to, understand? It changed my vision a little bit about that! Not that I do not suffer from it, I suffer, but I'm still learning, I'm still learning from it. But it causes me a big "thud" when I lose a patient".(Speech from the health worker – Silvia)

It is important to emphasize that even with previous professional experiences these workers have not been prepared, either in the training places or in the workspace of how to deal with this special albeit common component that is sharing, experiencing relationships, human relationships directly interconnected in the work that they perform.

Unpreparedness to deal with "emotional pain", with the suffering of the other and their own pain, is a reflection of the care model that is still employed, the Newtonian–Cartesian biomedical model. In this model the body is considered a machine with its parts analyzed and the role of health professionals has been to intervene physically and chemically. In this perspective, life understood in a holistic way, does not arise interest in the scientific way, as it deals only with what is measurable. This pattern of research and health work has become hegemonic and accepted as legitimate instrument of understanding life and defining the ways of the organized society, reducing perceptions from feelings, intuition, poetic inspiration and religious experience.

By focusing attention only on the proposal of hegemonic science, by focusing and prioritizing the use of equipment to the detriment of the knowledge of the complexity of living and the feelings of the cared human being, this model fails to incorporate the elements for individualization, fails to take into account that the therapeutic process is also a fabric of acting–feeling. Kóvacs<sup>20</sup> quotes Kubler–Ross when pointing out that the compassion of professionals is a developmental need, for all who work in the field of health, with compassion have the ability to "heal" anything. Kubler–Ross<sup>21</sup> considers that "if we could teach students the value of science and technology while teaching the art and science of human inter–relationship, human and total care of the patient, we would feel real progress" (p. 22).

In addition to preparation for working within this field, at the same time so old and so new, it was observed that the work with death leaves marks in the professionals. These marks deserve to be looked at closely, welcomed and processed in a team. This is an

activity experienced by mental health teams, in the areas of supervision / support, but there is little opportunities for other health workers.

The living work in act of death is the rationale for the possibility of incorporating another field of technologies, the meeting of people in relationships. It stands out as a surrendering situation. It is as if proximity to death, even of another, this constant living the vulnerability and human fragility touched so much that it that the fine line between being professional and being a person is broken. Death and the process of dying operate here as revitalizers of life, relationships, and the importance of human contact.

While working with death and with the process of dying, these professionals have faced questions that continue to be marginalized by the social body that resists reflections on human finitude. However, for them this question is latent. Thinking about the death of the others, causes an almost uncontrollable unfolding of their own condition of finitude.

The observed professionals expressed the primary importance of maintaining joy and good humor. Not as something forced, but as an expression of life, as a need, as a moment of respite to continue to walk among the pains and sufferings of those they care for, but still experiencing and cultivating lightness.

For Daniel Lins<sup>22</sup> "To feel cheerful, to meet with joy is part of the encounter", however it is difficult to be happy if the conscience is maintained. For this philosopher "joy must be a producer of unconsciousness and the person losing consciousness loses the organs". Losing the organs is the absence of systems, it is experiencing a body time that is totally controlled by the organism. In this case, the negative affections, the sadness are in the organism and in their presence it is difficult to be happy. The role of joy is not to deny death but to achieve, confronting the reality of death, "to work knowing death with the taste of joy". "To think about death with sad affections is laziness to be happy, to be joyful." Laziness is present because the existence of the other proves that I am not alone, provokes reflection already given by the imitation press. Joy is a social and desiring construction, joy is not given, it is an achievement, a construction.

In the construction of this path, built by walking it, respect for patients / users beliefs arises in many lines, and in this case it is independent whether the practitioner practices a religion or not. The expression of those who work in the CP team refers to respecting the movement of the person and the family when the movement exists or to try to offer something that accompanies them, which can be worded as spirituality, religion, faith or simply God.

With the knowledge that the experience presented them, or acting as they would have them do, they operate and carry the respect to the beliefs as a device to help in the handling / care of the patient and thus decreasing the suffering of the family.

### **Conclusion**

In this study, the professionals who work with people who have a foretold death operate not only, but primarily with light technologies, break with the status quo the, commonplaces of dying, and operate with the force of living work. Since relationships, sufferings, joys, self-knowledge from living with others pain, anguish, compassion, solidarity, offering the body and the mind as an instrument of care are exacerbated in these professionals, they are transformed, or rather, configured in this way of assisting as a substitute for the practices operated by the logic of care centered on the biomedical model.

The work of the care team related to death lies in the way they experience their feelings and the new experiences of self-knowledge that working with death provides them. What for many is pain for them does not cease to be, but they come in contact, live the external and internal pain and continue to observe, respectfully taking care of the person who dies.

The living work in the act of the professionals studied produces a complex and dense space to live the life of their patients and with them, without leaving aside the dead work that they also use. Palliative care workers presented discoveries and rediscovered,



recognized and denominated the importance of respecting the spaces of the other, their space autonomy, their individualities, persons and space, respected differences and domestic space. They are determined to live, learn and apprehend with joy, sadness, suffering, losses, gains, new friendships, new losses, new gains, self-knowledge and reflections. They lived the death while not forgetting life.

In the process of living the death of the other they reflected on their own death, their fragilities, vulnerabilities, their professional insertion and their place in the world. They have produced a new meaning for something that is clandestine, treating death as a natural movement of life, even in the face of terminality. Every day, with each new contact, they recreate the intense experimentation of the existence of life in the territory of death.

#### **Collaborators**

MS Chagas contributed to project concept, performed the research fieldwork, discussion of the results, review and approval of the final version of this paper. AL Abrahão participated in the discussion of results, review and approval of the final version of this paper.

#### **References**

1. Foucault M. *Microfísica do poder*. Rio de Janeiro: Paz e Terra; 2015.
2. Kóvacs MJ, coordenador. *Morte e desenvolvimento humano*. São Paulo: Casa do Psicólogo; 1992.
3. Elias N. *A solidão dos moribundos*. Rio de Janeiro: Jorge Zahar; 2001.
4. Morin E. *O homem e a morte*. Rio de Janeiro: Imago; 1997.
5. Pires D. Reestruturação produtiva e consequências para o trabalho em saúde. *Rev Bras Enferm*. 2000 [citado 20 Mar 2014]; 53(2):251-63. Disponível em: <http://www.scielo.br/pdf/reben/v53n2/v53n2a10.pdf>.
6. Merhy E. Do protagonismo/liberdade à captura: um dilema permanente do agir e algumas de suas implicações para a prática da vigilância à saúde. In: Diniz E, Pereira SD. *Curso básico em vigilância sanitária: unidade didático pedagógico I*. São Paulo: s.n.; 1998.57-77 [citado 20 Jan 2016]. Disponível em: <http://www.uff.br/saudecoletiva/professores/merhy/artigos-26.pdf>.
7. Merhy E. *Saúde: cartografia do trabalho vivo*. São Paulo: Hucitec; 2002.
8. Merhy E, coordenador. *Pesquisa implantação da atenção domiciliar no âmbito do SUS- modelagens a partir das experiências correntes: 2005-2008*. Brasília: Fundo Nacional de Saúde,

Ministério da Saúde; 2008 [citado 28 Jan 2016]. Disponível em:  
<http://www.medicina.ufrj.br/micropolitica/pesquisas/atencaodomiciliar/>.

9. VÍctoria CG, Knauth DR, Hassen MNA. Pesquisa qualitativa em Saúde: uma introdução ao tema. Porto Alegre: Tomo Editorial; 2000.

10. Bardin L. Análise de conteúdo. São Paulo: Edições 70; 2011.

11. Gil AC. Como elaborar projetos de pesquisa. 3a ed. São Paulo: Atlas; 1991.

12. Yin RK. Estudo de caso: planejamento e métodos. 3a ed. Porto Alegre: Bookman; 2005.

13. Kóvacs MJ. Morte e desenvolvimento humano. São Paulo: Casa do Psicólogo; 2002.

14. Vasconcelos EM, organizador. A espiritualidade no trabalho em saúde. São Paulo: Hucitec; 2005.

15. Alonso JP. Cuidados paliativos: entre la humanización y la medicalización del final de la vida. Cienc Saude Colet. 2013; 18(9):2541–8.

16. Cassorla RMS. Prefácio. In: Kóvacs MJ. Educação para a morte: temas e reflexões. São Paulo: Casa do Psicólogo, FAPESP; 2003.

17. Gleizer MA. Espinosa e a afetividade humana. Rio de Janeiro: Jorge Zahar; 2005.

18. Ortega F. Amizade e estética da existência em Foucault. Rio de Janeiro: Graal; 1999.

19. Chacra F. Metodologia centrada na primeira pessoa na experiência do vínculo. In: Barros NF, organizador. Pesquisa qualitativa em saúde: múltiplos olhares. Campinas: Komedi, UNICAMP; 2005.

20. Kóvacs MJ. Educação para a morte: temas e reflexões. São Paulo: Casa do Psicólogo, FAPESP; 2003.

21. Kubler-Ross E. Sobre a morte e o morrer: o que os doentes terminais têm para ensinar a médicos, enfermeiras, religiosos e aos seus próprios parentes. 9a ed. São Paulo: WMF Martins Fontes; 2008.

22. Lins D. A alegria como força revolucionária: ética e estética dos afetos. Palestra proferida no Café Filosófico – CPFL Cultura [citado 15 Dez 2015]. Disponível em:  
<http://www.cpflcultura.com.br/2009/02/11/daniel-lins-alegria-como-forca-revolucionaria-etica-e-estetica-dos-afetos/>.

Translated by Felix Rigoli