Rising to the medication's requirements: The experience of elderly cancer patients receiving palliative chemotherapy in the elective oncogeriatrics field

Rose-Anna Foley, Lucie Lechevalier Hurard, Annick Anchisi, Sandro Anchisi

School of Health Sciences (HESAV), University of Applied Sciences and Arts, Western Switzerland (HES-SO), Lausanne, Switzerland

Department of Epidemiology and Health Services, Center for General Medicine and Public Health, Unisanté, University of Lausanne, Switzerland

Oncology Service of the Hospital Center of Valais Romand (CHVR), Sion, Switzerland

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ABSTRACT

A new subfield of oncology has emerged in the last twenty years to raise awareness and address the specific needs of elderly cancer patients, a population that was long neglected in oncology. We sought to understand the individual experiences, as well as moral and social implications of considering elderly cancer patients as "treatable".

Following an anthropological critical interpretative approach focusing on practical and symbolic effects of chemotherapy in a rapidly evolving medical field, we conducted 20 semi-structured interviews and observations of medicine storage places at home among elderly cancer patients aged 70 and over in a clearly incurable situation receiving palliative chemotherapy. We used photographs representing paths as triggers in interviews, and compared the patients' views with those of 12 health professionals in oncology during a brief open-ended interview.

Elderly cancer patients consider themselves to be survivors and fighters. Their long trajectory is a result of their successful struggle and tolerance of the treatments allowing them to carry on. They continually observe their physical ability and test their resistance, they resist complaining and are grateful to have cancer at a late stage of life. By highlighting their active life rather than the treatment inconveniences, they show they are "young elderly" persons, capable of keeping active physically. They are treated precisely because they demonstrated that they had the physical and moral capacity to take the hit of the chemotherapy to their bodies and had the will to fight. The development of oncogeriatrics has enabled the treatment of the fittest cancer patients over 70, but the ethical debate to treat some elderly patients and not others, and decisions of therapeutic abstention facing frail elderly cancer patients remains an issue rarely discussed. This aspect should not be eluded by the important progress achieved in medicine facing cancer.

1. Introduction

1.1. Progress in cancer treatments and the recent focus on advanced cancer situations

As one of the contemporary symbols of severe illness (Sontag, 1983), cancer is considered one of the most feared and unfair illnesses, striking the population indiscriminately, from children to the elderly, with still insufficient understanding of its logic and its causes. Perhaps only Alzheimer's disease, with the dreaded loss of memory it causes concomitant with old age, raises similar fears in the collective imagination.
motherapy treatments less often than younger patients (Samet et al., 1983) and that chemotherapy must thus be adapted to this and complications due to cancer treatments differ in the elderly (Begg throughout the 1980s. Those studies showed that toxicity-related issues patients started in the 1970s (Butler and Gastel, 1979) and were continued challenge. The first clinical observations focusing on elderly cancer pa-

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span, a new subfield of oncology has emerged in the last twenty years focused on the treatment of elderly cancer patients, a population that was long neglected in oncology. Though it used to be commonly accepted to manage cancer up to the age of seventy (Extermann and Balducci, 2003), elderly patients were often excluded from cancer treatment programs. The first reason was because of their frailty, since they often experience several comorbidities that weaken them and reduce their chances of being able to receive chemotherapies (Ogle et al., 2000; Satariano and Silliman, 2003; Williams et al., 2016). Second, social impediments, such as low income and/or absence of relatives, have also made it difficult to consider elderly patients as able to go to a hospital to receive their treatments and pay for them, even in developed countries (Goodwin et al., 1993). Finally, social representations of the elderly, in which death is considered “in the nature of things” for them (Loffeier et al., 2017), do not facilitate care of elderly patients. In general, the elderly do not represent a priority target in curative medicine, since their re-

maining lifespan is limited. However, the mobilization of some physi-

cians and medical researchers at clinical and political levels has shed light on the specific question of cancer treatment for the elderly.

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cology community of the necessity of addressing the specific needs of the elderly, emphasizing the growing importance of old age and the in-

creasing demographic ageing of western societies. Rosemary Yancik, an epidemiologist at the National Cancer Institute (USA), who is considered one of the pioneer figures in oncogeriatrics, edited in 1983, “Perspectives on Prevention and Treatment of Cancer in the Elderly”, a book that broadly proposes a clinical research program able to face this major demographic challenge. The first clinical observations focusing on elderly cancer pa-

tients started in the 1970s (Butler and Gastel, 1979) and were continued throughout the 1980s. Those studies showed that toxicity-related issues and complications due to cancer treatments differ in the elderly (Begg and Carbone, 1983) and that chemotherapy must thus be adapted to this population and selected carefully (Balducci et al., 1988).

Several studies showed that elderly patients are given che-

motherapy treatments less often than younger patients (Samet et al.,

1986). Articles in the new field of oncogeriatrics were progressively superseded by more politically engaged papers denouncing forms of unequal treatment towards elderly patients. One article published in 1990 entitled, “Cancer in the elderly: why so badly treated?” (Fentiman et al., 1990), condemns the lack of consideration for elderly patients’ points of view regarding their choice to be treated considering their life expectancy and quality of life. It also notes that elderly patients are often excluded from clinical research mainly due to strict restrictions on comorbidities and the requirement of standard lab values in trials. This led to a serious lack of knowledge and clinical data regarding elderly cancer patients (Epstein, 2007). Calls for mobilization increased. For example, BJ Kennedy, the president of the American Society of Clinical Oncology, in the opening speech of the 1988 congress, encouraged the rapid development of oncogeriatrics. In the year 2000, the International Society for Geriatric Oncology (SIOG) was founded to improve the care of older cancer patients. Beginning in 2005, it organized an annual meeting. It also publishes the Journal of Geriatric Oncology, regularly issued since 2010 with thematic taskforces writing position papers on several topics to attract the attention of the medical community.

In the medical literature on the topic, statistics are often quoted to emphasize that cancer is one of the principal causes of mortality in the elderly and that half of all cancers are diagnosed after the age of 65 years. A common statement, quoted in one paper that has since become a powerful line, suggests, “If you’re not a pediatric oncologist, you’re a geriatric oncologist” (Lichtman et al., 2007, p.1821). However, the dif-

ferent mobilizations and associations created in oncogeriatrics did not necessarily aim at creating a new medical discipline per se. Rather, they sought a global mobilization of medical oncology around elderly patients, making them a central point of the future development of the discipline.

Together with the new therapeutic possibilities for treating cancer patients more safely and for longer, with an increase in patients’ life-

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1.2. Oncogeriatrics, a subfield addressing the needs of older cancer patients

Until the interwar period, therapeutic innovation in oncology was exclusively aimed at “curing” patients. It gave priority to patients who could heal and the early detection of cancers (Pinell, 2000). In the 1970s, the emergence of the palliative care movement and later of palliative medicine, a discipline dedicated to “caring” for incurable patients, delimited different regimes of medicine around cancer. On one side, oncology attempted to make live (Menni and Taibé, 2009) and help patients survive, and on the other side, palliative care aimed to let die and provide better quality of life for patients through therapeutic abstention and allowing them a time to die (Clark, 2007).

Nonetheless, the important therapeutic innovations in oncology in the last forty years have affected cancer trajectory patterns drastically. Declaring “there’s nothing else to do” in cancer care takes place much later than it did before (Muller and Koenig, 1988). The phase of metastasis apparition – signaling a generalized cancer and most often entering the incurable phase – can now be better controlled and ex-

tended. While cancer trajectories used to be characterized by a slow decline towards death, they are increasingly taking on the shape of a long plateau phase with a rapid decline at the end, shortly before death (Lynn and Adamson, 2003), enabling patients to stay at home until a few days before dying.

If there used to be a clear demarcation between the cure and care of cancer and a “passage” from one to the other, often represented by the transition from oncology to palliative care, such limits are now rather blurred, and the palliative phase has become complex, with increasing overlap between cure and care. Now, one can distinguish two palliative stages in cancer care, well described by French sociologist Isabelle Baszanger (2002):

- a “still therapeutic oncological palliative phase”, which corre-

sponds to situations where the ill person is incurable but can benefit from anticancer treatments to slow the growth of the damage caused by the illness, thus possibly lengthening life for months and some-

times years while ameliorating quality of life and controlling the
symptoms of an advanced cancer, and an “exclusive palliative phase” referring to the interruption of anticancer treatments with an emphasis on symptom and pain control, i.e., what palliative care and hospices traditionally offer.

This is an important turn for oncology, namely, actually treating an increasing number of people in advanced stages of cancer who are often incurable and thus in oncological palliative phases, many of whom are older than 70 years.

In this study, we focus on those elderly cancer patients who receive what can be considered palliative chemotherapies aimed at slowing the growth of cancer rather than curing it. Those patients were typically in a “still therapeutic oncological palliative phase” as defined above, progressing after at least one initial palliative systemic treatment.

2. Materials and methods

2.1. Theoretical paradigm: an anthropological critical interpretative approach

In medical anthropology, medicines are considered objects with pharmacological efficacy as well as objects invested with meaning by those who conceive them, prescribe them, deliver them or receive them (Van der Geest and Reynolds Whyte, 2003). Medicines are important symbolic mediators to oneself, others and the world. They can represent important landmarks in illness trajectories of persons experiencing uncertainty in the liminal state of having cancer (Little et al., 1998; Foley, 2016). Domestic pharmacies and private spaces are analyzers of the person’s way of relating to the illness (Fainzang, 2003).

This interpretative approach can be combined with a critical perspective: the first approach considers the meaning individuals give to their illness, as well as their representations, subjective experiences and practices. The second approach explores contextual and institutional aspects, which influence individuals’ narratives (Good, 1993) and regulate their representations and governance of their body (Fassin and Memmi, 2004). Although the starting point for our studies is the individual and his/her point of view expressed during an in-depth interview and observations at home, we link those interpretative elements to a critical angle examining the institutional transformations affecting individual experiences and daily life. Considered as the “third way” in medical anthropology (Massé, 2007), this critically interpretative approach proved to be well adapted to understand subjective experience in a rapidly evolving professional context—here, the medical field of cancer care and sub-field of oncogeriatrics.

2.2. Selection, setting and recruitment

We conducted a semi-structured interview and observations of medicine storage places among elderly metastatic cancer patients aged 70 and over in a clearly incurable situation receiving oral or intravenous systemic therapy after at least one systemic palliative treatment.

The patients selected were all treated by the oncology service of a French-speaking public hospital in an alpine region of Switzerland (Sion, Wallis). This service, whose chief physician (SA) is on the research team, occupies 3 sites (Sion, Martigny and Sierre) and cares for approx. 1700 patients a year.

After Japan, Switzerland has the highest life expectancy (81 years for men, 83 for women). Cancer care in Switzerland is provided by GPs at their office and by private or public hospitals, based on principles of free demand and supply. The Swiss Federal Law on Compulsory Health Care (LAMal) instituted a mandatory healthcare insurance for all persons living in Switzerland. The Law ensures that everyone has access to high quality, comprehensive health care. It offers the same range of services and benefits to all insured people, with no limitation based on age. Surgery, radiotherapy and systemic anticancer treatment, like the vast majority of services, are reimbursed on a fee-for-service system; nevertheless, travel costs are not refunded.

The chief physician on the team made an initial screening of eligible patients, and two researchers in medical anthropology (RAF) and sociology (AA) contacted the identified patients to ask them to take part in an interview, which was conducted face-to-face between May 2014 and February 2015.

The selection was more difficult than expected because of our specific criteria (being over 70 years old, having had at least one previous systemic treatment in the palliative stage, and still being treated, i.e., not being in a terminal phase). Recruitment was prolonged to obtain the purposive sample of 20 patients, which reflected a sufficient variety of situations in terms of cancer type (colon, uterus, breast, prostate, pancreas, ovaries, gastric, bladder, kidneys) gender, length of trajectory and age.

2.3. Data collection

We proceeded by conducting semi-structured interviews ranging from 1 h to an hour and a half. We used a photographic “trigger” representing the metaphor of a path. At the beginning of each interview, we showed patients 4 photographs of standard paths corresponding to the hypotheses we had of one long trajectory, one risky and uncertain path, one crossroad signaling choices and a “protected” tunnel hinting to guidance received from health professionals (see appendix). The choice and selection of those photographs is described elsewhere (Anchisi et al., 2018), showing that our hypotheses on illness trajectories were constructed in an ongoing iterative process, emerging from previous research results on elderly cancer patients (Anchisi et al., 2006, 2012; Foley et al., 2015).

We asked the elderly cancer patients included in this study, which one - if any of them - best represented their illness trajectory since they were diagnosed with cancer. We considered the photographs as a useful medium and a trigger (can opener) in qualitative research (Collier, 1986; Maresca and Meyer, 2013), giving access to patients’ own trajectory indirectly through the metaphor of the path and helping them view it as a whole, linked to past stages as well as to steps still to come. The interview questions sought to capture the different phases of the patients’ biographical and illness trajectory (life before illness, cancer diagnosis, major events and stages since, what is still to come, the lived experience of old age), while the observations sought to describe the spatial and temporal organizations of chemotherapy.

Twenty patients were met at home: 9 women and 11 men (ranging from 70 to 86 years of age, median age 75 years). The persons in our purposive sample had been in a palliative situation for 2 years on average. Some had cancer for over 12 years, whereas others were diagnosed with cancer only 1 year prior to the interview. Eleven of them were incurable upon diagnosis, while 9 of them passed through a substantial curative phase before relapsing and becoming incurable. During the recruitment phase, 3 persons refused to participate, 2 persons for linguistic reasons (they were German speakers). By the end of the study, 5 of the 20 persons interviewed had died of cancer (see Table 1).

In a complementary part of this study, we showed the same 4 photographs of paths to 12 health professionals in the oncology ward (7 nurses, 5 oncologists). We asked them, in a brief open-ended 15–25 min interview, to choose the path that best corresponded, in their opinion, to the trajectory of the elderly incurable cancer patients they encountered in the oncology ward. They were invited to tell us the key words that came to mind, which we reported manually and then coded (see Table 2).

The research project was approved by the clinical research ethics board of the canton of Valais, where the study was carried out.

2.4. Analysis

The contents of all 20 interviews and observations were audio recorded and fully transcribed, as well as field notes. The research team conducted a preliminary analysis by discussing and identifying emerging
The semantic analysis conducted on the basis of the same photographs shown to health professionals in the oncology ward, was detailed in Table 2 and discussed elsewhere (Anchisi et al., 2018). It showed striking differences in perceptions and was used in this article as a point of comparison with the elderly cancer patients’ discourses on the question of the stages of illness (curative and palliative) and the notion of having the choice (or not) to accept treatment.

3. Results

A first set of results shows that the experience of cancer in the elderly is a long moral and physical fight, in many ways similar to the experience of younger cancer patients taking chemotherapy. The

| Px = order of interview | Fictive name          | Profession, education | Family situation | Cancer type and duration of the palliative stage | Systemic therapies received during the palliative situation at the time of interview |
|-------------------------|-----------------------|-----------------------|------------------|-----------------------------------------------|---------------------------------------------------------------------------------|
| P1 73 years/M           | Mrs Catherine BULLIET| Secretary, without education | Married, 1 child | Metastatic kidney cancer for 5,5 years         | Sunitinib, pazopanib, évérolimus axitinib for 1 year, oxalamplate capécitabine |
| P2 75 years/M           | Mr Jean FABRI        | Electrician            | Married, 2 children | Metastatic rectum cancer for 4,3 years         | Irintotecan Sfu bevacizumab, oxalamplate capécitabine, irintotecan Sfu oxalamplate |
| P3 80 years/M           | Mr Pierre VARGA      | Bus driver             | Widower, a partner, 2 children | Metastatic gastric cancer for 13 months        | Irintotecan Sfu oxalamplate, Sfu oxalamplate 5fu, oxalamplate capécitabine |
| P4 82 years/F           | Mrs Maria VALTERIO   | Housewife              | Widower, 3 children | Diffuse large B cell lymphoma, recurrence since 4 years | Carboptaxine etoposide rituximab, rituximab bendamustine for 4,5 months |
| P5 78 years/F           | Mrs Anne RUBIN       | Teacher                | Single, no children | Locally advanced bladder cancer for 15 mois, metastatic since 10 months | Vinflunine, carboptaxine paclitaxel for 2 months, vinflunine capécitabine |
| P6 72 years/M           | Mr Angelo CAVELLI    | House painter          | Married, 2 children | Metastatic pancreatic cancer for 10 months    | Sfu, irintotecan oxalamplate, gémcitabine for 1 month, carboptaxine capécitabine |
| P7 77 years/M           | Mr Hans PISTOLETTI   | Businessman            | Married, 5 children | Urothelial metastatic ureter cancer for 19 months | Vinflunine, carboptaxine capécitabine, oxalamplate irintotecan Sfu for 1,5 months |
| P8 77 years/M           | Mr Michel FRANZEN    | Bus driver             | Widower, no children | Metastatic colonic cancer since 25 months      | Sfu oxalamplate, Sfu oxalamplate capécitabine Sfu for 3 months, oxalamplate capécitabine |
| P9 70 years/F           | Mrs Christine BELLON | Teacher                | Married, 2 children | Peritoneal carcinos of ovarian origin for 3 years | Paclitaxine carboptaxine gémcitabine bevacizumab, doxorubicine liposomal pégylé, topotecan for 4 months |
| P10 71 years/M          | Mr André EBENER      | Employee in tourism sector, without education | Married, no children | Peritoneal carcinos of gastric origin for 10 months | Docetaxel Sfu cisplatine, oxalamplate Sfu for 2 months, oxalamplate capécitabine capécitabine irintotecan Sfu for 2 months |
| P11 81 years/F          | Mrs Madeleine AMBIEIL| Hotel employee, without education | Widow, 4 children | Metastatic colonic cancer for 10 months with ostomy | Sfu oxalamplate, irintotecan oxalamplate, Sfu oxalamplate capécitabine |
| P12 79 years/M          | Mr Bernard MARCOZ    | Insurance agent, without education | Married, 2 children | Metastatic prostate cancer for 3 years and 7 months | Lh-Rh analogue, Lh-Rh bicalutamide docetaxel for 2 months |
| P13 72 years/M          | Mr Robert JORDAN     | Auto-body repairman    | Married, 2 children | Prostate cancer, loco-regional recurrence since 3 years, metastatic since 10 months (peritoneal carcinos) | Lh-Rh analogue, Lh-Rh bicalutamide for 10 months, docetaxel for 2 months |
| P14 72 years/M          | Mr René MEYER        | Teacher                | Married, 3 children | Metastatic prostate cancer for 5 years         | Lh-Rh analogue, Lh-Rh bicalutamide inhibite du cytochrome Cyp17, radium 223 for 1,5 months |
| P15 78 years/M          | Mr Marc ARNOLD       | Engineer in chemistry  | Married, 3 children | Metastatic prostate cancer for 21 months       | Lh-Rh analogue, Lh-Rh bicalutamide inhibite du cytochrome Cyp17, radium 223 for 1,5 months |
| P16 72 years/F          | Mrs Denise SOLA      | Teacher                | Widow, no children | Metastatic pancreas cancer for 8 months       | Sfu oxalplante, irintotecan gémcitabine nabpaclitaxel for 2 months |
| P17 72 years/M          | Mr Raymond IMFELD    | Engineer in physics    | Single, no children | Prostate cancer locally advanced for 8 years, metastatic for 6 months | Lh-Rh analogue docetaxel for 2 months, letrozole |
| P18 81 years/F          | Mrs Suzanne MICHEL   | Farmer                 | Married, 1 child | Breast cancer                                   | Letrozole, fulvestrant for 2 months, carboplatine etoposide rituximab bevacizumab |
| P19 70 years/F          | Mrs Simone LENER     | Bank employee          | Widow, a partner, no children | Metastatic for 3 years and 4 months           | Carboplatine etoposide rituximab bevacizumab, carboplatine gémcitabine for 3 months |
| P20 86 years/F          | Mrs Isabelle ASPER   | Chief of small company | Widow, 2 children | Metastatic colon cancer for 20 months with ostomy | Sfu irintotecan en cours for 3 months |

themes in an ongoing process during data collection. Once all interviews and observations were complete, a computer-assisted analysis was carried out. Interviews and observations were coded separately by one researcher, and cross-checked by the other medical anthropologist using the software Atlas.ti (see list of themes and codes in Table 2). Following an iterative and flexible process (Beaud and Weber, 1997), key themes appearing throughout the interviews and observations were identified, compared and discussed. The medical doctor on the team only accessed the anonymized data at this stage of the analysis.

The semantic analysis conducted on the basis of the same photographs shown to health professionals in the oncology ward, was
second set of results, however, hints toward particular constraints and the fragile situation of battling against cancer while being old. The third set of results reveals the social load of being elderly and the moral obligation not to complain about having cancer at a late stage in life.

3.1. Surviving and beating the treatment: a long, steep path

When they were questioned about the path they followed since they fell ill and its major stages, a majority of patients (17/20) chose the long and winding uphill road to describe their experience without ever referring to it using words such as “curative” or “palliative”, though several of them spoke spontaneously of the moment when the metastases were found. Those results contrast with health professionals’ views: several of them (6/12) believed the elderly incurable patients’ they encountered were following a “palliative”, “flat”, “calm” and “peaceful” path.

The elderly patients emphasized going beyond the bleak prognosis they had been given that predicted a short life expectancy. Most of them feel that they have stood firm and are amazed that they are still alive after several months or years. This sentiment was expressed by most persons interviewed, including Catherine Bulliet (fictive name), a 73-year-old woman with kidney cancer:

“I was operated 7 years ago, in October, and I had been told I'd live until February the next year, so sometimes I annoy the Doctor a bit and tell him, "you see, I'm still here" (laughter).”

Everything experienced in daily life takes a positive flavor and is a surprise, as expressed by Mr. René Meyer:

“It's rare that I am worried, it's annoying because I love life, I would like to keep on going as long as possible. With my wife we have many activities, we travel, we take pictures (…), now I'm part of the committee of a photographic association … I have a good appetite, I love life, I love traveling, I still do traditional photographs, I'm a dinosaur.”

This type of discourse unveils a positive and active way of living.

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**Table 2**

List of themes and codes (interviews, observations & health professionals’ views).

| Themes                                  | Codes                                      | Sub-codes                      |
|-----------------------------------------|--------------------------------------------|--------------------------------|
| Trajectories and stages of illness      | Choice of path                             | Path 1, path 2, path 3, path 4  |
| Announcing diagnosis                   | Who/when/after which symptoms health professionals |                              |
| People around                           | Role of relatives                          |                               |
| Important stages and key events         | Changes of medicines                       |                               |
| Death                                   | Metastases                                 |                               |
| Biographical trajectory (before illness and other life events) | Professional and family life | Cancer one possible cause |
| Previous illnesses                      | Occupation, marital status                 |                               |
| Fast good health                        | illness, death of relatives                |                               |
| Old age before illness                  | Healthy lifestyle                          |                               |
| Healthy old age (no comorbidities)      | Accelerated                                |                               |
| Representations of illness, self, body and medicines | Representations of cancer | Not allowed to complain |
| Representations of self                 | Metaphors                                  |                               |
| Representations of body                 | Feeling it/it not                          |                               |
| Representations of medicines            | Talking, thinking about it                 |                               |
| Observations of daily organization around medicines | Felt effects of chemotherapy | Origins                        |
| Photograph 1 (long)                    | Loss of weight                             |                               |
| 5 persons, 4 nurses (> 8 yrs practice, all women), 1 assistant doctor (> 6 months, man). | Able to receive chemo | |
| Photograph 2 (tunnel)                   | Planning                                   |                               |
| 2 persons                               | Blood tests                                |                               |
| 1 doctor (> 5 years, man), 1 nurse (> 5 years, woman) | Forgetting to take chemo | |
| Photograph 3 (crossroad)               | Storage places                             |                               |
| 4 persons                               | Usage, efficacy                            |                               |
| 3 doctors (> 2-6 years, 2 men, 1 woman), 1 research nurse (> 1 year, woman) | Practical support | |
| Photograph 4                            | Talk/not about illness                     |                               |
| 1 nurse (> 1 year, man)                 | Burden                                     |                               |
| Health professionals' views of trajectories: choice of one photograph | Representations of cancer | Heavy treatments |
| Photograph 1 (long)                    | Choice, possible, quality of life, directions, peaceful, palliative, serene, sad, quiet, flat, calm | |
| 5 persons, 4 nurses (> 8 yrs practice, all women), 1 assistant doctor (> 6 months, man). | Changes, length, duration, perspective, move forward winding, long, hard, winding, turns, uphill. | |
| Photograph 2 (tunnel)                   | Less heavy, less effort, test, last stage, lighting, flat, calm | |
| 2 persons                               | Choice, possible, quality of life, directions, peaceful, palliative, serene, sad, quiet, flat, calm. | |
| 1 doctor (> 5 years, man), 1 nurse (> 5 years, woman) | Difficulty, dangerosity, treatments. Tiring, risky | |
| Photograph 3 (crossroad)               | Secured.                                   |                               |
| 4 persons                               |                                           |                               |
| 3 doctors (> 2-6 years, 2 men, 1 woman), 1 research nurse (> 1 year, woman) | | |
| Photograph 4                            |                                           |                               |
| 1 nurse (> 1 year, man)                 |                                           |                               |
with advanced cancer while living at home. Mr. Jean Fabri, 72 years old with cancer of the rectum, reflects that his path has remained in many ways the same as before he had cancer:

“It’s a long path but not a hard one. Yes, because I told you I was able to do all my activities as I used to, for example, last year I did about 40 days of skiing, you see?”

Having the same activities as in the past is reassuring, and living as before is strongly linked to the ability to battle against the medication. The patients’ road is broad if and as long as they can receive treatment. Although the interviewed elderly patients also had to learn to live with painful technical interventions, such as ostomy pouches and port-a-caths, most felt they were facing a silent illness. Even when they could feel their tumor (for example, when bending down), most of them did not feel pain. Its progression was thus difficult to detect, whereas they directly felt the effects of chemotherapy:

“First I have to tell you I have never felt ill. I have the illness but I never felt my illness, I don’t know what it’s like. I never suffered from it. But I had trouble afterwards with the chemotherapies. That yes.” (Mr. Jean Fabri, 72 years, cancer of the rectum).

The representation of their cancer is of an invisible illness that “spreads”, “burns” or “infects” the body or “flourishes as in a vegetable garden”, as two elderly persons put it. The elderly patients made no distinction in potency or strength between curative and palliative chemotherapy, whereas the oncologists viewed palliative chemotherapy as an overall less aggressive treatment. Chemotherapy, regardless of type, is represented in the patients’ discourses as unequivocally the worst, strongest and most toxic medicine, in contrast to hormone therapy, x-rays, or nuclear medicine, which they refer to as lighter.

Starting chemotherapy was often associated with moving to a “heavy” stage of the illness. Some of the health professionals’ discourses reinforce such representations—that the way is wearisome with chemotherapy—as Mrs. Anne Rubin (78 years old, with bladder cancer), explains:

“The surgeon told me, ‘you’re embarking upon the way of the cross’. That was the hardest time because I had to accept chemo, I had to accept all those painful treatments, I didn’t know where I was going, I didn’t know much.

From the patients’ perspective, their path has been a fight against the treatments—to tolerate them, one after the other. These representations correspond to how anthropologists and historians describe chemotherapy, i.e., medicines as harmful as the disease itself (Pouchelle, 2002), killing the degenerative cells in the living body (Peter, 2004).

Looking back, the attempts to find “the right treatment” with the least side effects were important stages. Mrs. Simone Lener, a 70-year-old with uterine cancer says significantly:

“You have to bounce back; it doesn’t happen right away, it’s one treatment after the other”.

Some of them thought they were going to die from the major side effects they experienced. Mrs. Madeleine Ambiel, 81 years old with metastatic colon cancer, explains:

“Now I’m fine, but first they gave me such a strong chemo, I said, I’m going to die, I had no strength whatsoever”.

Mrs. Catherine Bulliet reflects on the rhythm of taking and pausing the medication and the fact that the medications made her ill:

“The hard times of that medicine, when I paused the treatment, I had a two-week break, so that was fantastic, I put on weight again and when I started being in good form I had to start it all again” (Mrs. Catherine Bulliet, 73 years, metastatic kidney cancer).

Some regretted having to interrupt a treatment because their body could not take it:

“If I had been able to eat well, I think I would have tolerated the Sutent … It’s a very good treatment I think, it’s a pity I had to stop it” (Mrs. Catherine Bulliet, 73 years, metastatic kidney cancer).

The fight against the medicine is linked to their body’s ability to tolerate the medicine. This is at the forefront rather than the fight against the illness itself. As shown in studies conducted among younger patients, the treatment makes them ill and leaves social signs and stigmas, whereas the illness itself is invisible (Sarradon-Eck and Pellegrini, 2012). Cancer is incomprehensible and escapes the patients’ understanding. In this study, however, not only was the discovery of the illness silent, but its aggravation was hardly ever felt in the body.

Most of the persons interviewed delegate knowledge about their illness to health professionals. The latter are generally highly esteemed. Patients express gratitude for the “excellent doctors” who “listen to you” and “understand you”, even if the most critical admit, as Mrs. Anne Rubin (78 years, bladder cancer) does, that facing doctors, “we are very docile”. They have little control over the choice of the treatments they are administered or over the illness itself, which they cannot act on other than by receiving chemotherapy.

In the absence of knowledge about the illness and its evolution, the patients share a common point of reference: waiting for the blood tests results before receiving chemotherapy. This is a crucial event for most of the elderly patients in the sample. The platelet and leucocyte levels determine whether the patient will be able to continue receiving chemotherapy and be treated. Through these tests, the ill persons have an indication as to whether their body can tolerate the treatment or not during this “follow-up”, which is circumscribed and can be reassuring. If the “platelets are good”, this means to the patients that the illness has not invaded the whole body, whereas in the doctors’ eyes, this event is not as revealing regarding the progression of the illness as patients assume it to be. The extent to which the illness has progressed must be evaluated through other means, such as laboratory tests and scans. However, the elderly patients interviewed believe that the primary reason the doctor changes their medication is not progression of their illness but the fact they did not tolerate the previous medication.

3.2. Being a fighter and testing one’s aged body on a day-to-day basis

While most health professionals in the oncology ward held the viewpoint that elderly cancer patients in a palliative stage could choose to receive their chemotherapy, not one elderly cancer patient in our sample selected the photograph of a crossroad, signaling their choice to continue taking their medication, whereas 4 health professionals chose that photograph (see Table 2). The patients’ concern is rather that they are put to the test of climbing a long, steep road.

The proof they can withstand the treatment is found in the performance of their daily activities and in the maintenance of a healthy lifestyle, as well as in mental resilience. The central self-representation of being a “fighter” is highly valorized. For example, Mrs. Christine Bellon declared, despite experiencing acute pain due to polyarthritides, that she has mental strength she had underestimated:

“I must say I took things better than (…) I was more solid than I thought I was. I thought to myself “it’s over, at Christmas, it’s over”, but straight after I reacted, I thought “in any case he [the cancer] isn’t the one ruling the world and we’ll see what happens, and I’m going to fight (…) Is it worth it to fight, I think that if we have inner strength that helps us, then we have to use it, it’s no point ruminating on the illness” (Mrs Christine Bellon, 70 years old, with peritoneal carcinosis).

Mr. Hans Pistolleti, a 75-year-old with urethral cancer, notes the importance of mental strength in fighting against illness and depression:

“So then I strengthened my head, my brain, with the idea to fight.”
The identity as a fighter is clearly linked to a past good health status and for many of the patients corresponds to a way of living in general and of enduring adversity. Some describe a current “healthy” old age with few comorbidities, despite their incurable cancer. They describe two different areas of health: a general & a cancer state of health.

The idea that they should conceive of their general health situation as independent of their cancer situation is a conception professionals share and encourage. Mrs. Denise Sola, a 72-year-old with pancreatic adenocarcinoma, assesses her situation:

“Because otherwise I have a very good health, I don’t have diabetes, I don’t have hypertension, I don’t have cholesterol, things like that, my health is rather good. So the oncologist said ‘we’ve got to battle because you are in good health’; I said ‘yes, apart from that (laughter). So I’m lucky because it’s true I was never really sick in my entire life, that’s it finally’.

From an oncological point of view, the patients are in an “in-between” situation: they responded badly or transiently to a prior treatment but have a reasonably good general condition.

This distinction was clearly observed in the domestic pharmacies of elderly cancer patients in their homes: cancer-associated treatments were always stored in spaces separate from other medications, such as those prescribed for age-associated problems (hypertension, diabetes, heart failure, arthritis). Those results are consistent with previous results found among elderly cancer patients taking oral chemotherapy (Anchisi et al., 2012; Foley et al., 2013). Although often considered by elderly cancer patients as “poisoned candy”, which showed that cancer could be considered as involving “lighter” and simpler care at home, the medication invaded their domestic space and interfered with their daily family and social life as they tried to maintain hope in the face of death.

Ethnographic observations in our previous research showed that places in the house where the chemotherapy are stored were different from others. They were highly symbolic e.g., in the cellar to distance the medicine from the household, or with their strong alcohol because it is toxic and must not be found by children. Still others kept the medicine in the centre of the house among family photographs and altars, to help them see and remember it. In this study, we found similar symbolic references stretching to cancer-associated medicines, objects and supplies, such as those needed for ostomy pouches, which were stored in private bathrooms, whereas more common cancer associated medicines were kept in the kitchen for immediate access and practical reasons.

Most interviewed persons adopt a stance that they have “to move”, keep busy and eat well. If they stop, if they stay on their couch, then they are doomed. For many, activating one’s body can be achieved through sport (hiking, skiing, going to the gym, swimming). This stance is supported by the Leagues against cancer, and the notion of keeping hope and spirits up even at an advanced stage of cancer is a central value in oncology (Del Vecchio Good et al., 1990; Saillant, 1990; McMullin and Weiner, 2009; Soum-Pouyalet et al., 2009).

Mr. Pierre Varga, 80 years old with gastric cancer, did not change much in his daily life:

“I can still do everything, I can work in the garden, I can do some DIY, I look after the trees a bit, I spend some time everywhere, with really no problem”.

Moving is about maintaining the same life rhythm, as Mr. Marc Arnold, a 78-year-old with prostate adenocarcinoma who goes to the gym, states:

“As long as I can do everything as usual, it means it’s all fine”.

Mr. Raymond Imfeld, 72 years old with prostate carcinoma, has noticed changes while walking up his stairs. Mr. Jean Fabri goes mountain hiking and observes his breathing and fatigue:

“So I did some tests while walking up hill”.

These activities allow them to observe their physical ability and see if the illness has weakened the body much.

3.3. Being old and having cancer: a lesser evil

The positive discourses are often strongly linked to the fact of being old, which seems to help participants see cancer as less severe, since their old age also generates frailty and ultimately leads to death. They had lived a long life before they were diagnosed with cancer, and being ill is part of old age. Furthermore, most of the elderly cancer patients interviewed were not particularly anxious about dying. Death was on the horizon whether cancer was part of the picture or not. Mr. Pierre Varga explains that cancer is only one of the plausible causes of death he has to face: “At my age, from one day to another I can have a heart attack, I won’t necessarily die of cancer, we all agree upon that. I take things as they come (…)”

For others who were interviewed, being old helped them relativize the diagnosis:

On this matter, Mrs. Catherine Bulliet (73 years, metastatic kidney cancer) says, “But you know, they told me that and it didn’t hit me at all (…) I phoned my husband and said, I have cancer, but because of the age I was, I thought to myself “too bad” and that’s all. Even now, I’m not scared, the other day I even told the doctor “I don’t have cancer”.

Some of the interviewed persons said they were grateful that cancer fell on them because they were “taking the load” from younger persons. They have integrated a representation of cancer as a collective scourge that can hit anybody, from children to active and finally retired persons. Since it must happen to someone, it is rather a good thing, in their opinion, that it happened to someone as old as them who had been lucky to live a long life as a “healthy person” before being diagnosed with cancer. In some ways, they believe it is more of a shame when cancer hits younger people, as their bodies are less “worn out”. Several of the persons interviewed explained they were deeply moved when they met younger cancer patients in the oncology ward, as if their situation was different than that of the younger patients. For example, Mrs. Christine Bellon (70 years old, with peritoneal carcinosis) said,

“You know, seeing the others who are younger really shocks me”.

Being old when having cancer thus seems to be a lesser evil and a way of generating social fairness in the face of this unjust illness. Nevertheless, the interviewees’ discourses can also reveal how much they have internalized negative representations of old age, i.e., that, in a way, their life counts for less than that of a younger patient.

The participants believe that their survivor’s trajectory has much to do with their positive attitude. The recurrence of affirmations such as “one has to battle”, “we have to keep our spirits up”, and “I can’t complain”, could however, hint towards some weight on their shoulders, pressure to put on a good face and battle on despite their situation. Moreover, the fact that it seems to them a rather good outcome to have cancer in their old age seems to add to the importance to remain positive.

4. Discussion

The elderly patients with advanced cancer we interviewed rarely complained about their situation or expressed their suffering. The interview mainly served to strengthen the building of a discourse about one's body and oneself as a fighter, an identity highly valued by them. If their illness was silent from the start, its progression was unfelt too. The terms “curative” or “palliative” are not useful labels to them. These patients are still fighting and are susceptible to the discourse shared among oncology health professionals that a strong active body better fights against cancer. The battle to remain treated seems in many ways similar to the hard work younger cancer and chronic patients have to face (May, 2006), with symptoms they feel are predominantly due to chemotherapy and not to their tumors.

Cancer care is the area of medicine in which military metaphors are most used: cancer is the enemy, you have to fight against it, and chemotherapy is a powerful weapon to do that (Del Vecchio Good et al.,
The history of chemotherapy discovery dates to World War I, when nitrogen gas, used to poison the enemy, was discovered to interrupt white cell reproduction. Chemotherapy thus originated as a deadly weapon and encapsulates the military metaphor. As raised by Slobod & Fuks, “when medicine is seen as war, patients may believe that becoming healthy is only a matter of “fighting” hard enough. But, who loses when disease “triumphs”?“ (2012, p. 144).

The risk is that patients feel strongly responsible for their situation and feel the need to endure the treatment no matter the cost. In this study, elderly patients have widely internalized moral attitudes and behaviors about staying healthy and having a fighter’s attitude in their daily activities.

As far as elderly cancer patients are concerned, it is interesting to see that the image of being a “fighter” and the need to battle on are in contrast to sociological theories of “dépris” being characteristic of old age trajectories (Caradec, 2007; Membrado and Salord, 2009). The elderly cancer patients never mention this progressive letting go of the environing world often experienced by elderly persons. Globally, it seems that the cancer experience takes over the old age experience. Remaining active to fight against the illness through their treatment seems to overshadow the ideas of decline and of growing old. We can assume that this lived experience of advanced cancer, very anchored in the present time and involving an active body, and described in a homogenous way by most of the interviewed elderly persons, has to do with the convergence of old age and chemotherapy.

Patients tend not feel old age as strongly because they are too busy fighting to tolerate their medications. However, it seems crucial to put this assertion in perspective by noting the pressure the elderly cancer patients seem to feel of having to be active and live as younger persons.

The fact that these patients correspond to a portion of elderly cancer patients who have been selected to receive chemotherapy treatment despite their advanced age and incurable situation must be borne in mind. By focusing on palliative cancer situations of persons above 70 years of age, we grew aware that these patients represented a still rare field of oncology practice and are, in some ways, the oncogeriatrics “champions”. Their homogenous discourses led us to reflect on what characterizes elderly cancer “treated” patients. As reported by some of the patients interviewed and then confirmed by the oncologists in the ward, one of them being in our interdisciplinary research team, the patients treated with palliative chemotherapy have a general good health status with little co-morbidities and are treated precisely because they demonstrated that they had the physical and moral capacity, i.e, the will to fight, to take the hit of the chemotherapy treatment to their bodies despite incurability.

In oncology it is not chronological age that matters but physiological age—the way age has altered the body of each individual. In a way, cancer care, by treating elderly persons, is more and more moving to patient-centered care within an interdisciplinary network of professionals, promoting self-empowerment and patient reported outcomes.

A qualitative study conducted in a French pilot unit of collaborating oncology and geriatrics specialists (Sifer-Rivière et al., 2010; Sifer-Rivière et al., 2011), the creation of which was promoted by successive public health plans (Maraninchi, 2009), shows how geriatric assessments led by collaborating oncology and geriatrics specialists repartition patients according to their level of vulnerability. The geriatricians are invested with the responsibility of demonstrating that patients are not too old to be treated. On the other hand, the oncologists are concerned with the discourse on equal rights to cancer care access and look after patients qualified as only elderly, i.e., capable of being treated for cancer like younger cancer patients because of their low vulnerability.

Nevertheless, oncologists tend to defer to the geriatrics specialists and consider that cancer treatment is irrelevant for patients who present strong dependency and impaired cognitive functions. If the gained life expectancy with the treatment implies reduced quality of life or more reduced autonomy, then chemotherapy can be undesirable (Fried et al., 2002).

As shown by Kentish-Barnes (2007), the confrontation of medical progress with moral imperatives place the physician in front of the choice to know what is technically possible to do and what is humanly reasonable to decide. Interestingly, if the health professionals in oncology present palliative chemotherapy as a choice to the elderly cancer patients, the elderly patients mostly feel they have to accept the opportunity given to them. They have conform attitudes and are grateful to receive treatment despite their age.

In current medicine, it seems the choice to be treated is increasingly handed off to the patients and their relatives (Mol, 2008), and in this case, the responsibility to choose falls on the elderly patient’s body, which will be able or will not be able to rise to the medication’s requirements.

Although it is seldom discussed in the oncology literature, the decision of therapeutic abstention facing frail elderly cancer patients is an important issue. The development of oncogeriatrics has enabled the treatment of the fittest cancer patients over 70, but the ethical debate of when to stop and enter an “exclusive palliative phase” results in crucial decision making facing many other patients.

The moral reasoning at stake, justified by the idea of respecting the natural course of old age while considering the quality of life the treatment will enable, is close to that found in other medical domains where the limits of life and death and medical decisions are important, such as in intensive care (Timmermans, 1998) and general medicine (Muller, 1992). Through resuscitative efforts and the use of reanimation codes in patients’ files, health professionals select which patients are given full “curative” treatment and which are not. Such studies show that there is a strong risk of inequality in death for those with low social value, among whom elderly patients are an important group.

Although there are more and more social actors who take a position on life and death decisions (assisted suicide and euthanasia movements, organ donors associations, patient organizations), our societies have few answers to such questions of arbitrary reasoning around the limits of life-sustaining treatments and technologies. It still mainly remains the responsibility of physicians to invent the norms for when to treat and when to stop treating (Slomka, 1992; Kentish-Barnes, 2007).

The medical fields relevant to elderly cancer patients “share” and “place” patients according to their physical and mental ability to receive chemotherapy. The ethical dilemmas faced are rarely discussed, despite the fact that physicians in such fields decide, on a regular basis, which patients it is ethical to make live and which patients they should let die.

In this context, elderly cancer patients’ ways of presenting themselves are without a doubt linked to the division in place between oncology and geriatrics: highlighting their active life rather than the treatment inconveniences, they show they are “young elderly” persons, fighters, capable of keeping active physically in the same way they lived prior to being diagnosed with cancer. They are not only fighting against the treatments, they are also battling against aging. By being able to incarnate this identity, they show that they are worthy of being treated.

5. Conclusions

More than ever before, cancers are well controlled and their treatments allow people to live at home and remain active even when they are older than 70 and in an incurable stage of their illness.

The elderly cancer patients treated with palliative chemotherapy are optimistic and have energy to continue with their active lives despite advanced cancer. They are living proof of cancer care achievements, and chemotherapy in palliative situations is an emblem of medical progress. Nonetheless, a closer look at the experience of elderly persons taking palliative chemotherapy reveals that they also have to constantly evaluate their body, have the moral attitude of a fighter, resist complaining and be grateful to have cancer at a late stage of life.

Health professionals in oncology are confident for the elderly.
patients receiving palliative chemotherapy, but they rarely discuss their
decisions to treat the fittest elderly patients and not others in oncology
settings and oncogeriatrics. This aspect should not be eluded by the
important progress achieved by medicine facing cancer.

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Appendix. Photographs used as interview triggers (in order: 1, 2, 3, 4)
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