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Patients receiving ambulatory care: a problematic autonomy situation

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Abstract

This article addresses the issue of the autonomy of patients who are not treated in standard situations of hospitalisation in institutions, but who receive ambulatory care. Academic and institutional discourses both suggest that the development of out-of-hospital care delivery models promotes patient autonomy. Through a qualitative study based on semi-structured interviews of cancer patients treated using ambulatory chemotherapy in a French hospital we show that some of the constraints usually encountered by patients receiving care in institutions are also observed in patients receiving ambulatory care. They experience a form of cognitive isolation regarding access to information about their health, and their social life appears to be institutionalised.

Key words : Autonomy; outpatient; medical care institutions; ambulatory care; patient isolation; sociology

Introduction

The number of patients treated as part of a hospital-in-the-home program designed to deliver hospital care, such as palliative care or treatment for neurodegenerative diseases, increased by nearly 80% between 2005 and 2008 in France (National association of French home hospitalisation institutions [FNEHAD], 2009). Concurrently, the availability of outpatient options and the development of different forms of oral chemotherapy have resulted in no more than 9% of cancer patients requiring full hospitalisation (French national cancer institute [INCa], 2010). Not only has the average length of hospital stay fallen but classic hospitalisation patterns, where care is delivered in a hospital setting, are being replaced by other, more cost-effective ways of providing medical treatment, such as home hospitalisation (HH) or outpatient care for a growing number of pathologies including the most severe kinds

(cancer, AIDS, cardiovascular diseases) (Carricaburu & Ménoret, 2005). According to Schweyer, hospitals, whose initial purpose was to admit patients, now tend to reduce as much as possible their activity as places of care, a structural conversion he describes as shifting "*from a stay without care to care without a stay*" (Schweyer, 2003, p241).

Due to the emphasis on the cost of health care, the impact of the new care delivery models on the health system has become the focus of much economic research projects. As a consequence, economic literature reviews were conducted as early as the 1980s on this topic (for example, see Berk & Chalmers, 1981). As for other areas of social sciences, the main studies on care delivery models are more recent and have dealt with the consequences of the 'outpatient shift' and the development of Hospital-in-the-Home on medical staff and care organisation (Bonneville, 2006 ; Diaz, 2000 ; Pérodeau & Côté, 2002). But as indicated in a 2003 review of scientific literature (Duke & Street, 2003), few studies have addressed the consequences of these types of systems from the patients' point of view.

A priori the evolution of health care delivery models made possible by technological and medical advances should prove to be a positive factor and an opportunity for users to avoid lengthy stays: hospitals often being described in sociological literature as places of confinement and institutional isolation where patients, faced with the prospect of increased dependency, lose their former "external" status (Arras & Neveloff Dubler, 1994; Goffman, 1961). The HH or outpatient models reflects the will to reduce the average length of hospital stays. A 2009 report based on a study by the National Association of HH Institutions on information systems and health technologies, states that HH is "*primarily a patient's choice. It is the response to the wish expressed by a given patient to regain control of his or her illness and treatment and to receive appropriate medical care in a familiar environment*" (FNEHAD, 2009, p32). Caplan and other academic researchers with an interest in patient care delivery share this point of view. Caplan stated in a comparative home/hospital study that it is preferable for patients to be spared the need to adapt to the hospital culture, remaining in a familiar environment and keeping some form of routine instead (Caplan et al., 1999).

However new hospitalisation models are not unanimously acclaimed and some authors note that the urgent need to reduce health costs is taking precedence over any social, ethic or sanitary considerations (Duke & Street, 2003; Pousada, 1995). Since the existing literature has not dealt extensively with the transformations induced by the new health care delivery

models, we decided to focus our attention on the status of patients not confined to a medical institution: Does leaving the hospital premises actually mean reducing their dependency on the institution? Can patients limit their reliance on the hospital by using other available external resources such as family, physicians and the media?

In the first part of our study, based on sociological literature, we identify the constraints imposed by the institution on hospitalised patients and the loss of autonomy they generate. In the second part, we compare these with the results of an interview-based survey of outpatients treated for cancer in a hospital in the South of France. We show that some of the constraints usually encountered by patients receiving care in institutions are also observed in patients receiving ambulatory care: They experience a form of cognitive isolation regarding access to information about their health, and their social life appears to be institutionalised.

From hospitalisation to care outside hospital premises and the likely impact on patient status

Health sociology began to study the role of hospital institutions in the mid 20th century, and while acknowledging that their primary activity consists in delivering care to ill individuals their other functions, such as maintaining social order, also emerged as study topics (for example, see Parsons, 1957). According to Parsons the hospital institution makes it possible to watch and isolate the ill within a closed structure and therefore offers society a form of protection. The approach which consists in alienating the sick from society and consequently keeping them confined has been the object of many studies and works conducted within the framework of a general theory of institutions based on confinement principles. "*A large number of like-situated Individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life*" (Goffman, 1961, p11). This is a typical feature of what Goffman called "total institutions".

Other studies point to strong similarities between hospital institutions and other places of confinement (convents, boarding schools, prisons) from the staff's perspectives (Brooks, 2009; Cott, 1998; Pearlin, 1962) and the patients' perspectives (Clark & Bowling, 1989; Quirk & Lelliott, 2001; Wing, 1962). The alienation and ongoing scrutiny experienced by hospital patients results in the alteration of their social status: As they are admitted to hospital patients must give up their autonomy and enter a system which requires them to become

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strongly dependent on the institution. The change translates into limited contacts with the "outside world", subjection to the rules imposed by the hospital, and the scrutiny and subsequent interpretation of their behaviour according to institutional expectations. Patients also resign from their usual social roles and are relieved of a number of responsibilities (Arras & Neveloff Dubler, 1994). Since Strauss's negotiated order theory (Strauss et al., 1963) it has been widely accepted that the hospital should not be perceived as a set and immovable organisation where patients are arbitrarily assigned predefined roles and status without the possibility of negotiating. Despite this most of the time hospitalisation does induce a loss of autonomy. As Coenen-Huther put it after a "forced stay" in hospital (he "took advantage" of a hospital stay as a patient to write down observations about the institution and the sociability patterns), the hospital environment "*tears patients away from their universe and hurls them into an unfamiliar world where they can only retain a minimal part of their autonomy*" (Coenen-Huther, 1991, p141).

The two main types of constraints

Individuals admitted to hospital appear to lose the attributes that typically express autonomy, and acquire others that make them fit to be socialised in the hospital environment. Two types of constraints imposed on individuals may be taken into consideration to assess patient status within the hospital institution: the first is patient confinement and isolation from the outside world, and the second includes constraints consistent with the institutionalisation of their social life within the hospital premises.

Patient isolation includes being deprived of the privileges afforded by the outside world which seems more instrumental than confinement itself in the loss of their former status. Once hospitalised, individuals can no longer access a number of resources associated with autonomy. Coenen-Huther for instance, showed during his hospital stay that patients were not able to use the telephone at will. His experience dates back to 1991 and nowadays accessing a phone while hospitalised no longer constitutes an issue, but patients wishing to use other means of communication such as the Internet may face the same type of difficulties. Similarly, prohibiting or limiting visits from relatives to the patient's room also hinders communication with the outside world. Isolation as described here affects any sources of information that may exist concerning patient health. Once within the hospital walls, patients

can no longer request the advice and opinion of external professionals they may be acquainted with such as family physicians or specialists. They do not have a choice of persons to talk to, as is the case outside the hospital structure. The variety of external resources (Bury, 1982) that patients may use to effectively deal with their situation is no longer available to them. Care providers are, for the most part, arbitrarily appointed and as a result patients' options appear to be considerably narrowed down. This type of isolation is all the more controversial when patients who express the wish to consult with a different specialist or be transferred to a different place of care encounter a number of obstacles (Ménoret, 2007). Patient isolation therefore extends to information about their current state of health since individuals are stripped of their former medical resources.

As with isolation, indicators for the second type of constraints - those tied with the institutionalisation of social life - are also frequently quoted in sociological literature. For instance many studies indicate that social temporality in hospitals is structured by medical procedures and their effects, and by encounters with medical care providers (see for example, Jowsey et al., 2012; Naithani et al., 2008). It is the stream of X-rays, angiographies, cardiac tests, scans and other medical tests which pace the daily lives of patients. It is also the time spent waiting for results, the visits by doctors, nurses and other personnel, and the schedules imposed for getting up, going to bed, taking meals or medication. The imposed social temporality runs parallel with an infantilisation process (Coenen-Huther, 1991) based on rewards and sanctions which induces patients to behave as the institution demands. Even though these obligations may be bypassed, as Goffman suggested with the concept of secondary adjustments (Goffman, 1961), it is clearly in the interest of patients to comply with the requests of hospital staff in order to avoid being considered as "bad patients" or "problem patients" (Coser, 1962 ; Lorber, 1975). Finally, the institutionalisation of social life is made potent through a form of forced sociability where patients are led to interact with individuals they have not chosen to meet (sharing rooms, taking part in collective activities and undergoing tests in the same facilities).

In the light of these observations one may wonder what the patient's status is outside the hospital premises when receiving hospital-in-the-home services? Do the types of constraints usually experienced by patients, according to institutional sociology, disappear in the context of outpatient treatment or HH? One may expect to observe: (i) a drop in manifestations of isolation regarding health information resources (choice of health professionals, exchanges

with relatives and access to the media such as the Internet); (ii) a drop in manifestations of institutionalised social life, habitually reflected by imposed social temporality, certain forms of infantilisation and undesired sociability. In the following part, these types of constraints are analysed in the context of outpatient treatment.

Outpatient chemotherapy

The qualitative study

The study was carried out between 2009 and 2010 in a hospital department of a medium-sized city in Southern France where cancer patients are treated using ambulatory chemotherapy. This mode of treatment is favoured by oncologists as it makes it possible for patients to visit the hospital for only a few hours a day to receive intravenous treatment and meet with the oncologist before returning home. According to protocols, chemotherapy is administered one to four times a month. We interviewed 27 persons using semi-structured interview patterns. On the one hand, the interview concerned the issues patients may face as a result of the disease and its treatment (understanding the disease, its evolution, chemotherapy, side effects and nutrition). On the other hand it dealt with the resources mobilised or not by patients to address these issues (medical staff, the media, relatives, support groups), particularly in out-of-hospital situations.

These individuals were approached in the treatment room on the day they were scheduled to receive chemotherapy. Before each interview we introduced ourselves to the patient as sociologists participating with the hospital in a research project essentially centred on patient information. In order to dispel hospital-generated constraints we made it a point of underlining that we were not part of the medical team and that the content of the interviews we requested would remain anonymous. We considered carrying out the interviews in the patients' homes in an attempt to minimise the influence of the hospital setting, but patients repeatedly expressed the wish not to postpone the interviews. This study was conducted in compliance with French legislation and ethical guidelines, which are not as strong as in Anglo-Saxons countries (for example, ethic controls through Institutional Review Boards are scarce for sociological studies in France). Furthermore our methodology was reviewed by the

hospital's oncology department. All interviews were electronically recorded and transcribed to conduct a thematic analysis of the data.

Among the patients interviewed there was a slightly larger proportion of women (15 women to 12 men). They ranged in age from 23-82 (the median age being 62 years). All but one were retired or on disability leave. When their latest job was taken into consideration, it was observed that a large proportion of them (three quarters of the sample) belonged to the middle or working classes (textile workers, restaurant employees, warehousemen, daily life auxiliaries and secretaries). How they felt about their conditions varied greatly as some patients had just started treatment while others already had several years' experience with cancer (16 of them had begun their first treatment in the course of the past 12 months and 11 more than one year prior to that date). Five had been receiving treatment for more than three years. Cancers included breast, lung, uterus, pancreas, Hodgkin's disease, leukaemia.

Patients facing a form of cognitive isolation

A number of similarities emerge when the situation of outpatients and inpatients as described in the literature are compared using the elements of institutionalisation and isolation quoted above.

Many interviews indicate that patients rarely mobilise their resources. We observed through analysing the interviews that health professionals such as family physicians, specialists or pharmacists were rarely mobilised by patients for matters directly related to their cancer. Although patients do have contact with these health professionals, they do not seem to seek their advice as medical and health professionals with respect to their disease. The only opinions relevant to them are those of the hospital oncologist and, to a lesser extent, of the nurses working in the department. It appears that many outpatients do not use a source of information that they might have been expected to mobilise as a useful tool to build their independence towards the hospital institution. Even when talking about their disease to their family physicians, their exchanges remain relatively superficial, to which the following testimony by a patient first treated in 2002 attests :

" [about his family physician] *To me it's not his thing* [oncology]. *I let him know what I'm doing here, last time I saw him I gave him the names of the 4 drugs I was about to take, he was very pleased because he didn't know about them, he wrote the names down. It's almost*

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like I'm the one teaching him things, well if I can say so, I don't mean to imply that I know more than he does. I just consider he is not competent in that area, so I don't ask ". (Patient No 22. 62-year-old man, retired executive)

Patients may discuss their situation with their family physicians "*to get some comfort, to get it off my chest*" as another female patient put it (Patient 21. 68-year-old woman, retired factory worker), but they do not consider them as competent interlocutors where cancer is concerned. While hospital care providers encourage patients attending as outpatients to get in touch with their family physicians in the first place should they experience difficulties in the course of their treatments, our observation is that patients only comply with this instruction during the initial part of treatment, and subsequently largely ignore this resource. We also asked patients about two other possibilities of hospital decompartmentalisation: patient support groups and alternative forms of medicine (healers, for example). The first turned out not to have been used (none of the patients claimed to have attempted to contact a support group and more than half the individuals in our sample were unable to even quote the name of one); as for the second possibility, few patients claimed to have considered it and 2 out of 27 said they had used complementary therapies, but added that they quickly lost interest, as in the case of this patient (Patient No 25. 69-year-old woman, retired factory worker): "*You realise that they are wrong* [healers]*, that is not true what they say. Do not go to these people*".

Similarly, relatives do not prove to be a helpful resource in improving familiarisation with the range of available medical information sources. Two thirds of the cancer sufferers we interviewed have relatives who, through their personal or professional experience, could, if approached, provide them with information or tips concerning their diseases. A little under half the interviewees have individuals working in the medical field among their relatives (a daughter in her last year at medical school, a sister-in-law who is a nurse, doctors they are friends with). Patients might be expected to approach them for information on side effects or nutrition since relatives can be perceived as relational resources for health questions, as shown by Ferrand in his study on confidants (Ferrand, 2007) But we have observed their unwillingness to engage in a patient / care provider relationship. A patient indicated that she does not want to "*impose on them* [her doctor friends] *insofar as they are friends first and foremost*". She limits herself to simply "keeping them up to date", like the majority of interviewed patients. She added: "*We talk about books, movies, the Avignon festival where we go together and this sort of things, but definitely not... [cancer].*" (Patient No 17. 68-year-old

woman, retired from a middle-management position). In addition, relatives who are also former cancer sufferers might prove to be a valuable source of information on the disease (1/3 of the patients interviewed are concerned). But we notice that either contact is scarce, or there is an unwillingness to talk about cancer in order to avoid being stigmatised, as this quote indicates (Patient No 18. 40-year-old woman, middle-management position, on sick leave):

"I refuse to keep acting as someone who is ill. […] *It's important for me to meet with friends, to have conversations about topics other than disease. I also try to keep away from people who are or have been ill".*

Although relatives as a major emotional resource may be helpful in dealing with daily obligations (Bury, 1982; Carricaburu & Pierret, 1995; Smith & Midanik, 1980), they are not instrumental as diversifying sources of information on the disease and do not partake in discussing that information. From this perspective, although outpatients do not experience total physical and emotional isolation, they still face a form of cognitive isolation. Patients are faced with a single source of information originating in the hospital, which they must deal with on their own. Furthermore, certain patients are aware that their disease is, to some extent, a burden to their loved ones, which may be the reason why they choose to set limits to their relatives' involvement. Ambulatory care and HH have caused daily tasks to be transferred from the hospital to the relatives (Arras & Neveloff Dubler, 1994). As a matter of fact, the institution relieves hospitalised patients of part of their responsibilities, while relatives of patients receiving ambulatory care are expected to take charge of the household chores made harder to deal with by the disease.

Over the past few years the Internet as a tool of information has become prominent among the resources available to patients receiving out-of-hospital treatment. In 2011, 36% of the French used the Internet to seek information on diseases, injuries or nutrition against 13% in 2006 (Eurostat figure, 2012). Outpatients with an Internet connection at home might be expected to use this tool to gather information on their pathologies or their treatments, which would not be possible for them to do if hospitalised. But among the 17 patients interviewed who had an Internet connection, 3 of them were unwilling to use this source of information because "*you can't do that,* [or else] *you'll end up ill for good*" (Patient no 5. 76-year-old woman, retired employee), and as for the remaining 14, they claim that source of information turned out to be useless, as in the case of a patient in her 4th month of treatment (Patient No 8. 66-year-old woman, retired employee) :

" I looked it up on the Internet but that's dreadful. Whenever he found me on the Web, my husband rushed to see what I was doing. I looked up all my drugs and I thought: "What is *all this ?". It doesn't really help, we're not doctors. "*

While studies have shown that certain patients do not wish to access all the information they might avail themselves of at every stage of their disease (Leydon et al., 2000),those facing issues raised by cancer and outpatient treatment typically experience a need for information in the early stages. The vast majority of them want to understand how chemotherapy works, what their chances of recovery are and what side effects they should expect (Jenkins et al., 2001; McCaughan & Thompson, 2000). From this perspective, the Internet as a research tool could prove to be a valuable resource. However, except for one individual who, given his job as a nurse, claimed to be able to search through and understand information on the Web, most patients interviewed went "at first", *"just to have a look"*. Even those familiar with this tool experienced difficulties localising the information they were looking for and understanding it, and expressed their lack of confidence in such a source. They feared the information they accessed might be inaccurate or not consistent with their personal situation. A patient who recently started a chemotherapy protocol expressed those fears (Patient No18. 40-year-old woman, middle-management position, on sick leave):

"Dr M. advised me to look up the cancer league website, because it was the most appropriate. But I can't... I can't find what I want to know, I mean details and... […]. I think on the Internet one doesn't necessarily use the right words to carry out a search. What's hard actually is that we are individuals but when we face disease we become statistics. […] I didn't look anything up other than the cancer league because I want to avoid the wrong sources. I don't feel like coming across some nonsense, and then again being informed is nice but informed by what?".

Through such comments the uninitiated displayed their basic mistrust of any information available on the Internet, and the reliability of the source being questioned by scholars who had occasion to demonstrate that it varies greatly from one website to the next (Friedman et al., 2006; Hargrave et al., 2006). The vast majority of patients interviewed stated that even when they understand the information, they still found it difficult to assess its reliability and so to use the Internet with efficiency.

It appears that certain factors that cause hospitalised patients to be isolated also affect outpatients albeit in a different manner: External resources do exist in terms of multiple sources and treatment information (the Internet, relatives, family physicians, associations with individuals affected by a cancer), but are rarely mobilised. From this perspective, the situations of outpatients and confined patients are comparable. While outpatients are not confined properly speaking, they are cognitively isolated since hospitals and their actors remain the sole source of information concerning their disease. Although outside the premises of a health institution, they remain in many respects confined by the hospital system itself.

The institutionalisation of social life "outside hospital premises"

A different set of elements concerns the institutionalisation of patient's social life. The patients interviewed gave evidence of a form of social temporality ruled by hospital life. As in the case of hospitalised patients, those receiving treatment at home are subjected to the pace imposed by an institution which sets their appointments for chemotherapy sessions as well as the dates and places for tests to be carried out, generally leaving little room for negotiation. Individuals also have to endure the wait for answers (asked by phone or directly to hospital staff), for exam results and the medical decisions that ensue. The overall wait time is magnified by the wait time associated with phone use, as these two quotes indicate:

Patient No 19. 61-year-old woman, retired employee, 3rd chemotherapy session:

" I had a little trouble, I called up the hospital and of course I know, these poor people are working day and night and they kept me waiting with the music for 15 minutes and then I broke down, I hung up and the next day I got through the first time. But I don't judge them because I know…it's always the same, not enough staff, they just can't deal with all the patients ".

Patient No 17. 68-year-old woman, mid-management position, first treated for cancer in 2005:

" I'll sometimes make a call. Doctor P. will be doing her rounds already or seeing patients in her office and then she needs to call me back. So there I am at home waiting, not taking anybody's calls, people phone me and I hang up in a hurry…that's the most stressful for me, because I want the information and it is hard to get. […] *The only time I feel anxiety is when she needs to phone me, to give me a report. I could stand watch all day long beside the phone, and it's not pleasant for me or for anyone else."*

The pace of hospital life invades the privacy of the patients' homes. Although they are not confined to a hospital room, they live to the pace of the oncology department and organise their daily lives around the requirements of the institution. Of course the time constraints faced by patients treated at home are not as exacting as the ones hospitalised patients are subjected to, yet they are a constant burden, be they medical constraints (taking prescribed drugs, undergoing tests and receiving care) or constraints coming from the hospital organisation (staff holidays, opening hours, pace of work).

The infantilisation of patients compelled to behave as required by the institution is another indicator of institutionalisation and can to some extent be observed in outpatients. We found no evidence of hospital staff resorting to the praise and threats described by Coenen-Huther (1991) in order to influence the behaviour of hospitalised patients. But patients receiving ambulatory treatment also meet the expectations of their oncology department. They intend to be "good patients", the kind that do not disrupt the pace of the institution and do not antagonise staff. Most patients avoid placing what they see as annoying calls and do not ask many questions. As a result, they avoid expressing their anxiety about the physiological changes and constant pain induced by chemotherapy side-effects as stated by this patient (Patient 8. 66-year-old woman, retired employee):

"So many strange things happen when you are on chemotherapy, strange side effects, there are many of those [...]. It's good that after chemo they tell you you should expect other effects because you'll have been taking drugs for six months and your body still has to get rid of all this crap. It hurts but you don't dare say it, you don't want to be a coward with pain."

Another patient expresses the fear of disturbing the care providers (Patient No 22 - 62 year-old man, retired executive):

"I'm always afraid to disturb. So all right, when I need to set a different date for an appointment or something of the sort I can't really help it, but when I see what happens with the phone, some people will call up for no good reason. [...] I try to pay attention, I'm careful about that because I don't want to be a nuisance. [...] ". He imagines care providers might complain *"Stop being such a damn pain, we have more urgent things to do than answer the phone "*.

The treatment-related issues highlighted by a female patient on chemotherapy for the past three months show how the fear of disturbing hospital staff and coming across as an

" annoying " patient compelled her to adapt her behaviour to the institution's expectations. (Patient No 21. 68-year-old woman, retired worker) :

"*Those are things that I wonder about and I don't dare ask the oncologist for fear of being ridiculous, I don't want them to tell me don't be thinking so much or this and that, I just have to cope with it. I guess these poor doctors must be tired of people talking nonsense. […] I don't want to wear them down with questions they must be hearing all day long, I feel like I'm a softy and I sort of demand attention like a child.*"

" Infantilisation" takes place in a different manner outside the hospital. The institution takes charge of all the patients' needs and brings them step by step to a lower social status, making them dependant on the staff and subjecting them to a system of punishments / rewards (Coenen-Huther, 1991). Outside the institution a "paradoxical infantilisation" process can be observed: although patients themselves feel the need to comply with the institution's expectations, such "infantilisation" results from an approach which encourages self-reliance. Patients will be told by staff at the onset of chemotherapy that should any difficulties arise, they should contact their family physicians rather than the hospital. They are provided with a thin booklet containing information on their disease, their treatment, the potential side effects or nutrition, designed to bring them answers without needing to contact the hospital. So the institution prompts its patients to break free from hospital departments, but this in turn induces self-censorship and patients cease to acknowledge their own expectations as we have seen through the previous quote.

Lastly, where imposed sociability contributes to the institutionalisation of social life, similarities are not obvious between the situations encountered inside and outside the hospital. In the hospital, patients are bound to interact with individuals they have not chosen to meet and that are imposed on them by the institution on a daily basis. While in shared rooms or exam rooms physical intimacy and personal intimacy (identity, type of pathology, prognosis) are limited, the outpatients we interviewed did not give any evidence of this type of institution-imposed sociability. Outpatients are able to decide whether or not to have contact with the other patients, and so any relationship they may enter will be the result of elective affinities. These situations rarely occur (one female patient out of the 27 interviewed) as most of the individuals taking part in the survey preferred to avoid meeting patients who will inevitably mirror their situation as cancer sufferers. Withdrawing from imposed sociability, a positive experience according to patients, increases their cognitive isolation since they are no

longer in contact with other sufferers. So it appears that HH contributes to the fragmentation and individualisation of the hospital experience – a phenomenon already noted by Carricaburu and Ménoret (2005)

Discussion and conclusion

This research, prompted by a number of isolation and institutionalisation indicators suggested by the literature, clarifies the particular status of patients receiving treatment outside of a hospital institution.

Firstly, in light of our interviews and findings, it cannot be asserted that HH care delivery models make it possible for patients to remain in their familiar environment as claimed by certain institutional and academic researchers (cf. introduction Caplan et al., 1999; FNEHAD, 2009). We have noted that patients receiving care at home experience changes in their environment as the pace of hospital life sets in and informs their daily lives. A certain number of constraints usually encountered in a classic hospitalisation setting arise. It would be more appropriate to state that HH results in the invasion of patients' environments, rather than describing it as a care delivery model that protects patients from the discomfort and inconvenience associated with hospital institutions. The widely positive assessment of these care delivery systems needs to be nuanced as the lived experience of out-of-premises hospitalisation are contrary to those in the institutional rhetoric.

Furthermore, we noticed that patient dependence on hospital staff remained very strong, especially when trying to access information about their health. Far from diversifying sources, outpatient treatment models narrow the choices down. It appears that oncology staff remain the sole information providers regarding disease and treatment since patients do not engage with external health professionals such as their family doctor or a relative in patient care discussions. In addition, the Internet is perceived as lacking relevance as an information tool concerning their pathology. Inevitably this leads us to question the conclusions of certain authors who claim that the Internet empowers patients to take control of their disease and negotiate with their doctors (Eysenbach, 2003 ; Ziebland, 2004). Patients are left to their own devices. Having to process the information provided by hospital staff on their own, a form of cognitive isolation substitutes the physical isolation existing in institutions. HH models were originally designed to decompartmentalise information and enable patients to "regain control

over their disease and treatment" (FNEHAD, 2009), but the results of our study did not provide evidence to support this theory.

Additionally, there are conflicting issues related to outpatients suffering the effects of recurring exhortations to autonomy. As stated earlier we have observed that patients tend to practise self-censorship and that they refrain from voicing their needs. These phenomena may be attributed to modern-day domination processes which require individuals to become actors-authors of treatment delivery (Martucelli, 2004), and no longer follow the paths of classic disciplines as analysed by Foucault (Foucault, 1977). Patients treated outside hospital premises may not be forced to withdraw from the world and may not be infantilised as was the case in the past, but they are expected to develop self-control and self-govern their behaviour (Hache, 2007). This refers to the contemporary forms of power, which were analysed by Foucault through the concept of govermentality (Foucault, 2007). From an ethical and political perspective it would seem appropriate to ponder ways to "empower" patients, providing them with practical means to achieve autonomy, so that such exhortations, by definition subjected to the budget constraints of health care management, may actually induce positive changes.

In conclusion, our study fills a major gap in the branch of sociological research specifically devoted to the hospital experience and the alterations induced by the shift towards HH. However we must make clear that these observations result from the features of our field of study. On the one hand, the patients interviewed live for the most part in rural areas and belong to the lower middle classes, which may partly explain why they seldom resort to the resources available to them (the Internet, external health specialists) for information on their pathologies. The observations we made e.g., on self censorship phenomena regarding the formulation of enquiries addressed to care providers may turn out to be true only in the social environments we surveyed. On the other hand, the particular nature of the disease under study may partly explain the new form of dependence we described since, as Ménoret put it, *"oncology transfers little competence to its patients"* (Ménoret, 2007, p81). Outpatients may have more difficulty processing information relative to their pathology than other patients facing other types of pathologies, even in the case of patients undergoing cancer treatment for several years. Given the small number of studies dealing with the autonomy of patients treated outside hospital premises, our results need to be compared with the results of other studies

based on different environments, e.g. other types of pathologies or individuals issued from more privileged social backgrounds.

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