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Contribution of a preliminary socio-anthropological survey to the development of a therapeutic patient education programme for patients receiving oral chemotherapy

Véronique Régnier-Denois^{*}, Vanessa Rousset-Guarato, Alice Nourissat, Aurélie Bourmaud, Franck Chauvin

Service de Santé publique, Institut de Cancérologie de la Loire – CIC-EC Inserm 3, 108 bis avenue Albert Raimond 42271 Saint-Priest-En-Jarez, France

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Abstract – Introduction: For a long time patients with cancer receiving chemotherapy were 'captive', and were considered as passive during the administration of their treatment. The development of oral treatments over the last decade has considerably changed this situation. However, very little is known about the behaviour of the patients and the physicians in this new setting. Our team carried out a social anthropological survey on patients who were autonomous in the management of their oral chemotherapy, before developing a therapeutic patient educational programme. **Objectives:** The objective of the survey was to identify the mental representations and behaviour of patients and prescribing oncologists. **Methods:** The survey included 42 patients receiving oral chemotherapy and 10 oncologists from two cancer centres in the Rhône-Alpes region in France between January and March 2007. Different qualitative study methods were used: repeated focus groups and individual face-to-face or telephone interviews. **Results and discussion:** The results of this survey were used to develop the objectives for a therapeutic educational programme. The way patients managed their oral chemotherapy was found to be linked to their beliefs about the treatment efficacy and toxicity. The structure and contents of the educational sessions were adapted to take into consideration the identified representation.

Key words: therapeutic observance / qualitative survey / physician-patient relationship / cancer / drug treatment

Résumé – Apport d'une étude exploratoire socio-anthropologique dans la construction d'un programme d'éducation des patients traités par chimiothérapie orale. Introduction : Pendant longtemps, les patients traités en oncologie et plus précisément par chimiothérapie ont été des patients "captifs", considérés comme passifs lors de l'administration de leurs traitements. Le développement des traitements par voie orale durant la dernière décennie est un élément qui a considérablement changé cette réalité. Cependant, peu de données sont disponibles concernant les pratiques des patients et des médecins dans ce nouveau contexte. Pour élaborer un programme d'éducation thérapeutique, notre équipe a réalisé une enquête socio-anthropologique auprès de patients se trouvant en autonomie avec un traitement de chimiothérapie par voie orale. **Objectifs :** L'objectif de cette enquête était d'identifier les représentations mentales et les pratiques des patients et des oncologues prescripteurs. **Méthodes :** Elle a porté sur 42 patient(e)s sous chimiothérapie orale et 10 oncologues à partir de 2 centres spécialisés en cancérologie de la région Rhône-Alpes entre janvier et mars 2007. Diverses méthodes d'investigation qualitatives ont été employées : entretiens de groupe répétés, interviews en face en face et par téléphone. **Résultats et discussion :** Les résultats de cette enquête ont ensuite servis à l'élaboration des objectifs du programme éducatif. La question des pratiques autour des chimiothérapies orales s'est révélée liée à des croyances interrogeant les notions d'efficacité et de toxicité du médicament. Les méthodes et contenus des séances d'éducation ont été adaptés en fonction des représentations identifiées.

Mots clés : observance thérapeutique / enquête qualitative / relation médecin-malade / cancer / médicament

* Correspondence: Service de Santé publique, Institut de Cancérologie de la Loire – CIC-EC Inserm 3, 108 bis avenue Albert Raimond, 42271 Saint-Priest-en-Jarez France, veronique.regnier@icloire.fr. Véronique Régnier-Denois is the principal author, Vanessa Rousset-Guarato, wrote the therapeutic patient education programmes, Alice Nourissat, Aurélie Bourmaud reviewed and translated, Franck Chauvin wrote Discussion section and references. This study was funded by an unrestricted grant from Roche Laboratories as a feasibility study for an educational programme for patients receiving oral chemotherapy.

1 Introduction

Therapeutic educational programmes were initially developed for patients with chronic conditions, particularly diabetes and asthma, as the patients must play an active role in their treatment. In France, cancer was not considered as a chronic condition and educating patients was, and still is, only done in a small number of specific situations, often after ablative interventions such as laryngectomy or colostomy. Therapeutic advances in oncology have increased life expectancy and changed the therapeutic objectives, thus changing cancer to a chronic condition. These advances have produced complicated and diverse treatments with multiple secondary effects which are variable from one patient to another. The consequence of this is that the management of the patients has to evolve to be able to provide long term support.

Therapeutic educational programmes in oncology have been developed and implemented for about 20 years in the United States. They have mainly focused on the management of secondary effects from chemotherapy and on pain management. Anti-cancerous chemotherapy is responsible for a variety of well known short-term and long-term secondary effects (such as: fatigue, infection and fever, anaemia, oral mucositis, diarrhoea, constipation, nausea and vomiting, alopecia, haemorrhagic disorders, sexual dysfunction) whose incidence and severity are dependant on the treatment protocols and the patients. Pilot studies have already shown that therapeutic educational programmes in oncology can improve the management of secondary effects [1]. Fatigue is the most frequent secondary effect of these treatments, and it has the biggest impact on the patients' quality of life [2]. One randomised trial in women receiving adjuvant chemotherapy for early-stage breast cancer showed the short-term efficacy of an educational programme to help patients manage and accept fatigue due to their treatment [3]. Several educational programmes for patients with cancer for the management of pain have been implemented in English-speaking countries [4–6].

There are few systematic, evaluated therapeutic educational programmes in oncology in France, despite the available guidelines [5]. The first French national cancer plan emphasized the need to take into consideration the patients' information needs and the necessity to provide support to them, particularly when the diagnostic of cancer is announced. Pain management, psycho-oncology consultations and other care, known more generally as support care were developed in specialized units. The organisation of these units, known as 'DISSPO': *Dispositifs de Soins de Supports en Oncologie* (or Oncology Support Care Units) vary between the cancer centres. Patient drop-in and information centres (ERI¹) have been set-up in the National Cancer Centres and some university hospitals. They are staffed by non-medical personnel and the patients have access to information about the various cancers, treatment side effects, social services procedures, patient associations, etc. If Therapeutic Patient

Education (TPE) programmes initiatives for patients have been implemented in some specialized hospitals there have been very few publications allowing us to evaluate their efficacy or usefulness, or to compare the different strategies that could be used.

Oral chemotherapies in oncology have been available in the last decade and studies of educational programmes are more recent than those for pain management [7]. The therapeutic advantages of this type of treatment, coupled with its impact on treatment costs, and patients' preferences for this type of administration have contributed to their rapid development. Many of the chemotherapies currently administered by an intra-venous route are now available as a daily oral dose. In addition, the development of targeted therapies increases the number of major therapies that patients can take at home [8]. This involvement of patients in their treatment poses new problems for adherence and also for the surveillance of secondary effects and the respect of medical advice for follow-up. The efficacy of treatment, its lifelong use in some cases and the patients' safety are threatened by non adherence [9]. This new administration mode has also modified the relationship between patients and healthcare professionals and also has reduced the contact patients have with hospitals.

The most frequently aspect studied of the introduction of cancer oral chemotherapy is adherence, defined as the extent of the conformity to the recommendations for the treatment by the provider with respect to the timing, dosage, and frequency. Generally adherence is measured quantitatively as the respect of the treatment schedule by the patient using electronic pill boxes or self-reporting [10].

Within the Lyon Auvergne Rhône-Alpes cancer network, the regional centre for resources for cancer information, prevention and education (centre Hyg e) has developed and evaluated cancer TPE programmes. The team includes practitioners, public health physicians, sociologists and medical educators. The research programmes are developed using standardised methods and are evaluated using methods from clinical research programmes. The patient educational programmes are developed using a standardised five-step method proposed by the American National Cancer Institute and the Cancer Patient Education Network [11]. These are based on the classical WHO definition that distinguishes TPE as a systematic learning process centred on the patient from information that can be provided before treatment or when the patient asks for it. The global characteristic of the TPE programmes is also emphasized as it "should take into consideration not only the patients' coping mechanisms, their locus of control, their own representations of health and disease, and socio-cultural aspects, but also, the expressed and non-expressed objective and subjective needs of the patients" [12].

The recommendations from experts about TPE programmes for oral chemotherapy are not well developed, if we take the WHO definition into consideration. Those that do exist are focused on safety behaviour during the treatment course. The reference tool, the MOATT (MACSS Oral Agent Teaching Tool) is currently available in 11 languages and so is used widely in the world [13]. Although, it is emphasized in the

¹ Since 2001, 35 Espaces Rencontre Information opened in France.

introduction that the patients' characteristics and their disease should be taken into consideration, the tool simply provides a check list of information that should be provided to the patients and a list of instructions that should be given with the tool to evaluate how well the information has been understood. The first section contains key questions to assess the patient's knowledge of the treatment plan, current medications, and ability to obtain and take an oral cancer agent. The second section provides general patient teaching instructions applicable to all oral cancer agents, such as storage, handling, and disposal; identifying a system for remembering to take the oral cancer agent, and actions to take for various situations, such as a missed dose. The third section is used to provide drug-specific information, such as dose and schedule, side effects, and potential interactions. The last section lists questions that may be asked to assess the understanding of the information provided.

2 Objectives of the social anthropological survey

In the development of an educational programme targeted to patients taking into consideration their complex relationship with medication, other aspects should be taken into consideration:

- The patients' representations which are important in the meaning they give to the medication. The medication's action mode, indications, efficacy and side effects can be thought about by the patients with same logic that can be used for biomedicine, but can also be very different. For this aspect anthropology can help us to understand the complex relationship which form the links between the patients and the medication they are prescribed. S. Fainzang, in her book about the influence of cultural-religious roots on the perception of medication, showed how the adherence behaviour, self-medication and relationships with physicians are influenced by these roots [14]. Beyond these cultural-religious differences, in order to understand the pathology and the therapeutic indication, patients need to have their own representation of the physiology and the mode of action of the medication. These elements lead to a sort of quiz game in the interpretation of the body signs, for example for the side effects [15]. The relationship with the inner body is deeply modified by the experience of having a cancer. Surgery, medication, photographic representations from various examinations and the existence of a disease incorporated in a tumour or disseminated in metastatic lesions all participate in the patients' efforts to modify their relationship with their own bodies and which more globally involves self-image [16]. The concept of mode of action, efficacy and side effects are compared with collective, symbolic representations of medication, similar to the references for biomedicine and reinterpreted in the setting of their relationships with the healthcare world and their close circle of family and friends [17, 18]. Finding themselves in a situation of autonomy, confronted with a treatment which symbolises cancer: chemotherapy [19], and the representation of the disease,

their body, their medication and its mode of action represent the guides for action that we want to take into consideration, in this context [20].

- The way in which physicians provide information and prescribe also has an effect on the patients' representation of their medication, its efficacy and its management. The study reported by Ross showed the heterogeneity of the way physicians provide information and how the management difficulties are taken into consideration in the therapeutic relationship [21]. We must also look at physicians' behaviour during prescription since they have to deal with an administration mode that they do not know well and they do not have the traditional captive patient receiving chemotherapy. We need to ask questions about their ability to assess the patients' capacity for self-management of their treatment.

- Finally, it is important to clarify the medical representation of these new medications, but more importantly the representation for the impact of the new administration mode on the medical relationship. These relationships have an impact on the patients' needs for information and on the role the physicians should play in accompanying their patients in their autonomy [22].

3 Study methods

We focused our survey on a chemotherapy that is currently prescribed to patients with metastatic breast and colon cancer, and to a lesser extent to patients with colon cancer as an adjuvant treatment.

Two cancer specialised centres in the Rhône-Alpes region in France participated in this study which was carried out between January and March 2007. Patients identified from the physicians' consultation registers were contacted by the interviewer. We used two complementary methods: group and individual interviews. This crossed approach enabled us to collect transversal and pathway data which enriched the data collected (identification of the diversity, similarities and apprehension in relationship to the treatment). The patient survey involved four 2-h focus groups with four patients in each, held twice (16 patients) and individual interviews (either face-to-face or by phone) with 26 other patients. The focus groups allow discussion during which the participants justify their choices and their behaviour and so allow them to specify their representations and beliefs [23]. The individual 1-h interviews, either face-to-face or by telephone (8 patients) were used to explore particular themes, in terms of life trajectory. The variation in the length of the telephone interviews (20 to 60 min) was greater than that for the face-to-face interviews, and depended on the patients' being comfortable with this communication means; interviews of less than 15 min were not included. The semi-structured interview guides used aimed to facilitate an "interview" situation. The topics covered were: type of treatment; usefulness of their therapeutic pathway; treatment experiences; management of side effects; relationship with their oncologist; expectations for follow-up; relationships with their close family and friends. The questions were not restrictive

and the anthropological interview aimed to discover the patients' pathway, the representative associations, and the interview leader facilitated this exploration with the individual or with the group [24].

The same survey methods were used with the physicians, with a focus group of six prescribing oncologists defining specific themes that were then explored with four other oncologists during individual interviews. The topics covered with the oncologists were the selection criteria for the patients to whom oral chemotherapy was proposed, prescription behaviour and follow-up, their definition of adherence and how they manage their relationship with their patients for the aspects of adherence.

Several analytical steps were employed. Firstly, we used a comprehensive approach to connect the different elements of the discourse during each interview, and this was done for each group (patients and oncologists). Then the topics covered during the focus groups were used to do an initial structuring of the content analysis of the interviews after they had been dissected and the extracts coded.

4 Results

The patients' participation rate was 50%. The distance from the cancer centre and the treatments' secondary effects were the two main reasons for refusal. The characteristics of the patients are summarised in table I. The patients included were representative of the patients receiving this treatment, in terms of gender, age and type of cancer.

4.1 Representation and practices of oral chemotherapy by physicians

The first theme discussed by the oncologists involved the differences between methods for intravenous chemotherapy, carried out in hospital, under the surveillance of healthcare personnel and those for the prescription of oral chemotherapy. The latter are much less standardised; the dosage, the organisation of the medical follow-up and the information given to the patient are very different, depending on the oncologist, without them being aware of the differences. The representation of the efficacy of oral chemotherapy seems to have evolved, since medical oncologists now seem convinced that oral chemotherapy could be as good as intravenous treatment, although many were sceptical. The administration route still has an influence on its traceability and on the procedure of the administration.

The second theme concerns the fact that adherence is not discussed with the patients. Most of the physicians think that the importance of what is at stake with the treatment is sufficient to guarantee good adherence. There seems to be no doubt about adherence when the oral chemotherapy is prescribed, since, for them, the prescription formalises a therapeutic contract which put confidence in the centre of their relationship. The fear of over-adherence, due to forgetfulness, particularly in elderly patients was mentioned as an important concern for

Table I. Characteristics of the 42 patients included (16 in focus groups and 26 in individual interviews).

Characteristic	All patients N = 42
Gender	
Women	37
Men	5
Age (years)–median (min-max)	
45–55 years	9
56–65 years	12
66–75 years	13
75–80 years	4
> 80 years	4
Cancer Centre	
Centre 1	22
Centre 2	20
Type of cancer	
Metastatic breast	32
Metastatic colon	6
Adjuvant colon	4
Delay since onset of cancer	
≤ 5 years	20
≥ 6 years	22
Duration of oral chemotherapy	
< 6 months	18
6 to 12 months	14
> 12 months	10

oncologist prescribing oral chemotherapy. The concept of “experience” of the disease or of the treatment is an important element in the selection of patients by the oncologist for proposing oral chemotherapy.

The prescribers, therefore, select patients on the basis of their assessment of their cognitive status and the ability of their family to manage the treatment. In the selection of patients, the oncologists give priority to those who have already had intravenous chemotherapy, because they think these patients will have learnt to cope with secondary effects efficiently. On the contrary, reinforcement strategies for adherence are implemented by the oncologists when they feel that their patient may think that the oral chemotherapy is less efficacious than intravenous chemotherapy. They often use the argument that the treatment is novel, although it has been prescribed for many years. They can even use the argument that home-based treatment will provide an improved quality of life and comfort, and sometimes they provide less rational arguments aiming to convey a belief in the treatment's exceptional efficacy (it is magic!). During the initiation of the treatment, the secondary effects are sometimes minimised or even hidden, to encourage better treatment adherence.

4.2 Representation of oral chemotherapy by patients

During our interviews with the patients, the first theme discussed was problems with adherence. The patients said they

had few problems with forgetting or refusing to take their treatment. In contrast, three patients reported dosage errors because their pharmacist had not read the prescription properly.

Differences in the interpretation of the instructions for doses (30 min after a meal) were observed. This is directly related to their representation of the pharmacokinetics of the drug which plays a role in their interpretation of the instructions. Some patients took their treatment exactly 30 min after a meal, while others, who had not had any digestive problems, simply respected a delay of 12 h between each dose, without worrying about their meal. It should be noted that these instructions are important for the efficacy of the treatment and the risk of non-digestive secondary effects because of its pharmacological properties.

However, the management of secondary effects by the patients was an important aspect of oral chemotherapy. The patients reported episodes remarkable by the intensity of certain secondary effects when they coped by endurance and “grinning and bearing” it. For example, one 87-year-old woman, who suffered from oral mucositis, survived for 10 days by eating every other day, without being able to hydrate herself correctly, and thus taking life-threatening risks.

Other stories show that their communication about their secondary effects to the physician was either poor or absent. When they were asked about what motivated them not to respect the instructions given by their physician when the treatment was prescribed, it was clear that the relationship between toxicity and efficacy was central. This relationship constitutes a strong representative link that guides the patients in their management of the treatment and its secondary effects. Hence the secondary effects are felt to be positive and are interpreted as a sign of the treatment efficacy. When they suffer from important secondary effects, the patients fear that their physician will reduce the dose and also, therefore, the treatment efficacy will be lower. This is explained by the strong link that they establish in their representation of the mode of action of the treatment between the quantity taken and efficacy observed.

Finally, the patients’ experience of secondary effects from intravenous chemotherapy is a third, important element to take into consideration. Although the mode of action is different, the patients often compare the secondary effects from oral chemotherapy with those they experienced from intravenous chemotherapy. The patients reduce their alarm threshold and thus increase their risk of more important complications.

The patients surveyed had extremely different feelings concerning their self-efficacy about the self-management of their treatment. Worries about the responsibility for the treatment are frequent, particularly in the elderly patients. While oral administration is supposed to be less constraint than intravenous administration, some patients impose important constraints on their daily rhythm or their social life because they worry about forgetting to take their treatment or about not being able to follow the instructions. On the other hand, we observed that some patients allowed themselves an extreme autonomy in the management of their treatment. For example, one patient said he had stopped the systematic blood tests which should be done

before each treatment cycle because he judged it to be useless and heavy.

5 Discussion

The results from our qualitative survey confirmed that the follow-up of the prescription of oral chemotherapy practices are very variable and not really controlled [25]. They also show that the problem of treatment adherence is rarely discussed by either the oncologist or the patient during follow-up. This situation is surprising in the light of the results from several studies that show that, on the contrary, adherence is an inherent problem for the prescription of chemotherapy or hormone therapy [9, 26]. But this can be explained if the question of adherence is linked to a contract of confidence between the oncologist and the patient. As treatment adherence was tacitly introduced into the heart of the relationship, it cannot be discussed with danger. Patients having difficulties taking their treatment or suffering from side effects can find themselves in a difficult situation if they decided to talk with their physician. The concept of culpability linked to non-conformity with the physicians’ explicit expectations was developed by Ross [21].

From the physicians’ point of view, the lack of discussion with them about adherence, the feeling of self-efficacy and the non-communication about secondary effects are the strategies used to control the emotions of the patients and to attempt to suppress their anxiety [27]. It is particularly important in oncology to give patients’ confidence because of the uncertainty of the treatments and the aetiology. However, relying on this confidence to guarantee adherence is also uncertain because of the representations of the efficacy and toxicity of the medication as shown in the study. These representatives are much influenced by the belief in the treatment’s beneficial effect on cancer, which is a priority for sick people. The notion of toxicity is not developed by the physicians and is interpreted as the ‘price to pay’ for a cure or a stabilisation of their cancer by the patients. This interpretation is supported by the social representation of cancer against which we “make war or battle against” if there is some collateral damage. The body signs of this toxicity are thus minimised even re-interpreted as positive signs of the treatment efficacy. The medical strategies used to reinforce treatment adherence are based on avoidance of side effects (toxicity) due to the medication and consolidated the representations. The relational model also included the notion of a “good patient” corresponding to the expectations of the physician and worthy of the confidence that the physician has, as shown by the autonomy allowed for the oral treatment [28]. The persistence of these professional reflexes shows the difficulty that prescribers have to adapt for the integration and management of oral chemotherapy. It seems that a therapeutic education intervention is necessary in this situation [29, 30].

Input for therapeutic educational programme from the survey

Initially, it was planned to develop patient educational programmes about adherence with oral chemotherapy with a

focus on aspects concerning taking the treatment. This socio-anthropological survey has shown that the techniques proposed by the physicians to help understand the type of medical treatment (identification of a chemotherapy), good practice in management of treatment schema and the treatment schedule are very limited. The programme has thus been developed taking the elements of the qualitative study into consideration and integrating them in the educational objectives. Four principal themes have been defined:

1. With the patients, identify and then elaborate the representations of the disease, quality of life with the disease and the mode of action of the treatment on the disease, while integrating a specific reflection around the notions of treatment efficacy and toxicity for oral chemotherapy and its bodily signs.
2. Develop the skills necessary for self-surveillance and prevention of secondary effects specific to oral chemotherapy which re-introduce the bodily signs and their meaning – their link with treatment side effects and compare them with the patients' experience while receiving intravenous treatment.
3. Develop the skills necessary to know what to do in the event of toxicity from oral chemotherapy. In other words, make it possible to have an intervention to improve quality of life, in a body showing signs of toxicity that is compatible with the notion of treatment efficacy.
4. Develop skills for communication with their physician and family circle by working on the question of their respective expectations and roles, autonomy and the modifications in the identity of someone who is sick.

The programme was developed through meetings with healthcare educators trained to animate groups and motivation support. The first session occurs when the treatment is initiated. The programme starts with an individual meeting which results in an educational diagnosis taking into consideration the patients' understanding of the security advice but also their emotions (confidence, anxiety, locus of control) about their treatment and the support they can depend on in the event of any difficulties.

The second session involves a group meeting during which the representations of treatment efficacy, toxicity and what to do in different situations are debated collectively and discussion about their relationship with the physician(s), pharmacist and close circle of family and friends. Case studies based on the educational diagnosis are proposed by the educator, and by the patients participating in the session. The objective of the third meeting is to assess their experience with the treatment, to maintain and reinforce their learning about the management of their treatment and side effects. The reconstruction of their identity because of their cancer and the quality of the support available to them are also covered.

6 Conclusion

The patients adherence with treatments prescribed in oncology is an emerging problem which will grow as cancer

increasingly becomes a chronic condition and the number of oral chemotherapies increases. This problem is currently poorly managed in oncology departments where the model of the "captive" patient is largely present. In this setting, therapeutic patient education programmes seem to be a pertinent solution. A social anthropological survey is an essential starting point for the development of such programmes which should take into consideration the whole patients, the representation of their disease and the therapeutic mode of action and their relationships in the middle of the healthcare system. TPE programmes enable the patients' representations to be discovered and it is richer when the representations of the physicians and their manner of providing information to the patients are also taken into account. The educational objectives of such a programme could thus be based on solid data and would bring out the problems of adherence and take into account the underlying problems such as the representation of medication, unwillingness to follow medical advice, or the differences between the representations of patients and physicians about the treatments' side effects.

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