


*Psychic representation by patients or parents of oral
versus intravenous chemotherapy
in a paediatric and young adults oncologic unit
in France*

- S. SAlkhalaf, Nicole Delépine

www.nicoledelepine.fr

Why this interrogation

- If social representations of cancer are often studied , the chemotherapy itself as an object is rarely central
- furthermore the oral chemotherapy as transformation of the patient representation of the treatment seems to be forgotten

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- But these psychic representations are able to play a big role in the adherence or compliance to the treatment
 - and this adherence is the corner point of the feasibility of the oral chemotherapy

Goals of oral chemotherapy

- To improve quality of life of patients
- to improve their autonomy and avoid repetitive hospitalisations
- to decrease costs of multiple care in hospital
- to try to obtain a good efficiency



*Why introducing oral
chemotherapy*

Previous story of oral chemotherapy

- It is true that in an previous period
 - (1990-2005)
 - the oral forms were essentially used in **palliative care** without expressing it always
 - The patients discovered it secondarily
 - "by chance »
 - and lost confidence in their doctor

Previous story of oral chemotherapy and evolution

- But numerous oral new medicines appear in the market whose objective is the cure
 - (even if it remains un-said).
 - Their expensive costs would make the palliative optics absurd.
 - Things change fast, the psychic representation slowly

Theoretical benefits for the patient or parents

- Relative normalisation of life
- autonomisation in the management of the illness

A changing paradigm for cancer treatment



- Cancer now is recognized as a treatable chronic disease
- and new oral chemotherapy agents have been developed that offer targeted cancer treatment

- Patient adherence and monitoring can be challenging, and reimbursement issues abound. Oncology nurses play a key role in assessing, educating, and monitoring patients receiving oral chemotherapy. In addition, they may be involved in assisting patients with obtaining reimbursement and, in some cases, may be instrumental in locating patient assistance programs

Point of view of the doctor


- For the oncologists the choice of the mode of molecule administration is theoretically guided by its supposed efficiency on the targeted tumoral cells
- But some drugs are delivered without intravenous presentation and vice versa


Point of view of the patient

- Nevertheless, the feeling of the patients is very different from the one of doctors
- in particular the immediate psychic representation

immediate psychic representation

- the oral chemotherapy is felt as "light" thus probably ineffective and maybe palliative
- whereas the intravenous chemotherapy appears as part of « true treatments » with a curative aim

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- Few of the safeguards routinely used for infusion chemotherapy have been adopted for oral chemotherapy in US cancer centres. There is currently no consensus in these centres for what regards safe medication practices for oral chemotherapy.

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- Common malignancies can be treated with oral chemotherapy.¹ This offers patients unprecedented convenience compared with intravenous infusion therapy.^{2,3,4} Given the potential toxicities of oral chemotherapy and the importance of adherence for successful treatment, ensuring safe use of these drugs may require special safeguards

Immediate side effects for doctor and patients

- High frequency of anxiety of the patient and doctor
- immediately the passage to the oral chemotherapy appears
 - as a lost of chance
 - an abandon

Consequences of oral chemotherapy use

- The patient or parents have the responsibility for the administration without safety practices
- no control far from the hospital
- often in relation with a chronic evolution of the cancer

Our daily experience

- Everyday , we need a long work of explanation on the mode of action of molecules
- on the effort of laboratories to find oral forms allowing a better quality of life
- fewer hospitalizations
- lesser cost for the society

Our daily experience

- So the patient agrees to envisage our explanations rational and not as a medical lie.
- Sometimes, they accept it "rationally" but persists the initial feeling which reappears periodically of a "lesser" efficiency »
- even of a **renunciation with regard to their pathology, even to their existence**

Evolution: new drugs are often oral

- Nowadays, more and more oral anticancer chemotherapies are developed either for cytotoxic or new targeted drugs.
- But this relatively new route of administration in oncology leads to new problems in treatment management and particularly to ***non-compliance***

*Evolution: new drugs are often oral
new problem of non compliance*

- new problems in treatment management and particularly to non-compliance
- i.e. *the deviance of the actual way patients take their treatment with the prescription*

BMJ. 2007 February 24; 334(7590): 407.

Saul N Weingart

Center for Patient Safety, Dana-Farber Cancer Institute,
Boston, MA 02115, USA

- Our data indicate that prescribing, monitoring and coordinating pharmacy practices, and education of patients for oral chemotherapy vary substantially. Despite clinicians' concern about oral chemotherapies, there is no apparent consensus among oncology professionals about safe practices for these drugs. Safeguards used for infusion chemotherapy cannot be abandoned for oral treatment. The oncology community must define safe medication practices appropriate for oral chemotherapy, develop practice guidelines, and accelerate their adoption.
- What is already known on this topic
 - Although oncologists prescribe oral chemotherapy for many indications, little is known about associated safety practices
- What this study adds
 - Few of the safeguards in routine use for infusion chemotherapy have been adopted for oral chemotherapy

*Psychic bad representation : oral medicines
were palliative and nothing else*

- As numerous medicines arrive under oral shape (targeted therapies)
- it becomes indispensable to study this aspect of our prescription
- to examine the mechanisms of this hierarchy classification (partially false)
- We need to overcome gradually this obsolete idea.

For the future

- The use of the routinely safeguards

Limits of oral chemotherapy


- Use of the oral route is convenient and allows administration to take place at home or in non-traditional settings.
- But **nausea, difficulty swallowing, patient non adherence**
- **interactions with drugs and food, other pharmacokinetic factors**

Social limits of oral chemotherapy

- For the society
 - the high cost of treatment can present problems in using these agents by the oral route
 - when very expensive and not taken regularly

Paradox of new oral chemotherapy: targeted drugs

- the new drugs lead to inversion of the phenomena: initially oral chemo was given as palliative and inexpensive
- now as curative and highly expensive
- but the psychic representation doesn't change so quickly (a few years~~ 5)



*Risks of oral chemotherapy on
curable patients*

Use of oral versus systemic chemotherapy

- These results foresee the necessity of global simulations
 - **combining compliance**
 - **toxicity**
 - **efficacy modelling**
 - **psychic representation for patients and doctors**

Oral chemotherapy may pose a risk to patients

- because of a **narrow therapeutic index**
complex dosing regimen
- dispensing by community pharmacists
without prescription order review by an oncology pharmacist or nurse,
- **self-administration** at home or another non traditional setting
 - where patient monitoring is infrequent.

Oral chemotherapy may pose a risk to patients

- Errors in prescribing, dispensing, and administration
- **patient or caregiver misunderstandings** are potential problems with the use of oral chemotherapy
 - need to develop safe practices
- *BMJ* 1996;313:1219-1220 (16 Nov) **Non-compliance with oral chemotherapy in childhood leukaemia**

An overlooked and costly cause of late relapse

J S Lilleyman, L Lennard

- Outpatient antimetabolite treatment is inexpensive whereas salvage treatment for relapsed acute lymphoblastic leukaemia, still unsuccessful in most patients, is extremely costly. The inexorable trend to more intensive, toxic, and expensive first line treatment protocols might also be slowed down. And on a worldwide scale, anything that simplifies and reduces the cost of treatment will eventually lead to more children receiving potentially curative treatment.