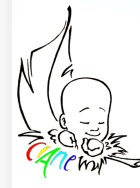


Supporting or questioning the perinatal health care system: which role is legitimate for a 21st Century citizen?

Collectif interassociatif autour de la naissance (CIANE, France)
(A coalition of perinatal agencies)

A presentation by Madeleine Akrich & Bernard Bel

<http://ciane.net>



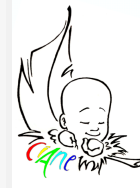
Part 1: A historical background

- During the 2nd half of the 20th Century, in France, evaluating critically medical interventions and protocols was mainly the task of health professionals.
- However, access to fertility control and to pain relief during childbirth (epidural) challenged this role of physicians as decision makers: they should also respect the choice of every woman.



A historical background (ctd)

- During the 1980-1990s, grassroots patient organisations (AIDS, cancer, rare diseases) contributed to a public debate aiming at redefining the relation between patients and their caregivers, which led to a new medical legal system, in 2002 (under minister Bernard Kouchner). The new approach emphasized the individual and collective rights of patients.
- However, consumers of maternity services acted marginally in this radical change.



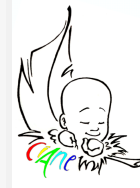
A historical background (ctd)

- During the 1950s, and further during the 1970-80s, self-support groups modified the relations between patients and doctors. Among these, *La Leche League* (1956 in the USA) and AIDS patient organisations in the 1980s played a major role.
- Still, perinatal agencies shared little visibility in the public space.



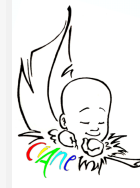
A historical background (end)

- In France, consumers of the health care system gained power during the 1990s which led to the emergence of a 'health democracy'. With this turn of mind, *États généraux de la santé* (an encounter of all actors of the health system) were organised in 1998-1999. Consumers of maternity services participated in a marginal way.
- Nonetheless, in the early 2000s, a few childbirth societies had become aware of new opportunities offered by the growing health democracy, in spite of the fact that they were kept apart from mutations of the participation of patient-citizens in the health care system.



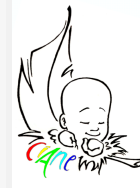
Part 2: Where is the legitimacy?

- Historical perinatal agencies
- The Internet
- An example: the *Cesarine* group, a self-help grassroots association
- The case of the episiotomy



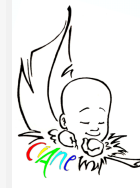
Where is the legitimacy? (ctd)

- A new profile for 'activists'
- Ciane, investing the political space (2003): *merging historical societies with Internet groups*
- Three major objectives: to inform, to identify improvement strategies, to communicate and be recognized as an interlocutor on behalf of users facing public authorities.
- Referring to authoritative institutions is fully compatible with the mission of representing (all consumers).



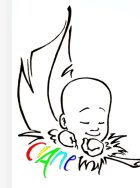
Where is the legitimacy? (ctd)

- The critical assessment of medical practice is conducive to building a collective speech strengthening the role of representatives of consumers.
- Legitimizing consumers' representation beyond their legitimacy endowed by Law: the need for a training.
- Self-training provides the necessary distance for expressing collective points of view.
- When consumers acquire knowledge they increase the quality of dialogue with professional caregivers.



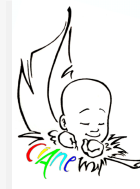
Where is the legitimacy? (end)

- The legitimacy of criticizing medical practice is not acknowledged by all actors...
- Many patient organisations reject it;
- Grassroot consumers have doubts;
- Health professionals are divided over this issue.
- Conclusion: *challenging practice is not an end in itself!*



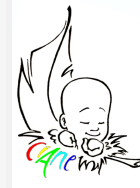
Part 3: Which tools are available and what are the consumers' skills?

- Evidence-based medicine (EBM) is not an easy-to-access topic, nor is its methodology taken for granted by health practitioners. Reading and interpreting academic publications to take them into account in medical practice is a radical change of medical 'culture'. It is also one for patients' culture.
- Consumers are aware that medical practice should combine clinical experience with factual evidence found in the literature. Therefore they estimate that they should also articulate their position with a critical analysis of this factual evidence.
- Achieving a high standard of critical analysis has become possible due to the sharing of complimentary competences between activists belonging to different groups under the CIANE coalition.



Which tools are available and what are the consumers' skills? (ctd)

- How non-professionals access publications, how they read and analyse them:
 - Accessing bibliographical databases
 - Accessing the contents of publications
 - Translating
 - Interpreting methodological and statistical data



Which tools are available and what are the consumers' skills? (end)

- How non-professionals deal with publications to communicate, synthesize, criticize their contents and incorporate this knowledge in collective reflection and action:
 - The AFAR cooperative bibliographical database
 - Watch and exhaustive search
 - The capacity to criticize publications, their syntheses and the referentials they are based on
 - An example with labour induction at term in the absence of clinical signs