

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 childbirth organisations)

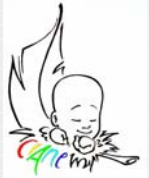
A presentation by Madeleine Akrich & Bernard Bel

<http://ciane.net>



Feminists challenging medical expertise

- Until 1980 at least, 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.



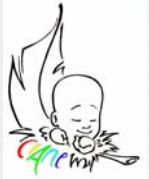
The rise of patient organisations

- During the 1980-1990s, grassroot patient organisations (AIDS, 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.
- Until 2002, consumers of maternity services acted marginally in this radical change.
- But the 2002 law created some opportunity for the emergence of new childbirth movement



Mixing up experience with expertise as a source for legitimacy

- Pioneering childbirth organisations
Personal experience, beliefs, confidence etc.
- The Internet-> becoming aware of the importance of medical reasoning to be credible
Discussion lists, forums, blogs...
- An example: the *Cesarine* group, a self-help grassroot association (2005)
- The case of the episiotomy
1st World Respecting Childbirth Week (2004)



From legitimacy to accreditation

- A new profile for ‘activists’
- Ciane, investing the political space (2003): *merging pioneering childbirth organisations with Internet groups*
- Four major objectives: to inform, to identify improvement strategies, to communicate and be recognized as an interlocutor on behalf of consumers facing public authorities.
- Entering the institutional game is fully compatible with the mission of representing (all) consumers. => *CIANE’s accreditation*



Building a substantiated collective position

The critical assessment of medical practice – together with keeping in contact with the women's preoccupations – is conducive to building a **collective position** strengthening the role of representatives of consumers.

- Debating provides the necessary **distance** for expressing collective points of view.
- Legitimizing consumers' representation beyond their legitimacy endowed by Law: the need for a **training**.
- When consumers' representatives acquire knowledge they increase the quality of **dialogue** with professional caregivers: they should act as translators between consumers and professionals



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 for our medical 'culture'. (It is also one for patients' cultures.)
- 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 **complementary competences** between activists belonging to different groups under the CIANE coalition.



Accessing the information

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



Dealing with the information

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



Limitations to this critical approach

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: changing perinatal health policy requires the support of all actors!



To conclude...

Consumers and professionals do not necessarily reach the same conclusions after reading scientific data. For this reason there should always remain a *space for discussion* between 'expert doctors' and 'expert patients'.

A key issue is that medical protocols are often derived from strict interpretations of statistics for the sake of minimizing *medical* and *litigation* risks whereas consumers insist on taking into account the extreme *diversity* of parents' points of views.