Elena Skoko, Italy

“Evidence-based activism in childbirth. Two successful cases: 'neonatal cord blood' and 'obstetric violence'”
“Evidence-based activism”

Evidence-based activism

*Patients’ and health activists’ groups’ focus on knowledge production and knowledge mobilisation in the governance of health issues*
Evidence-based activism

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These groups engage with, and articulate a variety of credentialed knowledge and ‘experiential knowledge’ with a view to explore concerned people’s situations, to make themselves part and parcel of the networks of expertise on their conditions in their national contexts, and to elaborate evidence on the issues they deem important to address both at an individual and a collective level.

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Patients’ and health activists’ groups’ focus on knowledge production and knowledge mobilisation in the governance of health issues

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Entails a collective inquiry associating patients/activists and specialists/professionals in the conjoint fabrics of scientific statements and political claims.

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Evidence-based activism

In contrast to health movements which contest institutions from the outside, patients’ and activists’ groups which embrace ‘evidence-based activism’ work ‘from within’ to imagine new epistemic and political appraisal of their causes and conditions.

Patients’ organisations which engage in evidence-based activism collect experiences and build experiential knowledge, and that is how they give shape to concerned groups and delineate their preoccupations.

They articulate credentialed knowledge with experiential knowledge in order to make the latter politically relevant, e.g. to capture other stakeholders’ interests and raise health issues.

To achieve these epistemic shifts, patients’ organisations make themselves part and parcel of networks of expertise with credentialed experts and collaborate to some extent with health authorities as well as medical professionals. This leads them to adopt a ‘reformist’ rather than a purely confrontational perspective.

The causes defended by patients’ organisations, the definition of their conditions, and the identities of concerned people are the outcome of these knowledge-related activities rather than their causes.

Through this process, they usually reframe what is at stake, destabilising existing understandings of conditions and problems and resulting in the identification of zones of ‘undone science’ (Hess 2009; Frickel et al. 2010), thus inextricably linking patients’ organisations’ involvement in politics of health to politics of knowledge.

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CoRDiN
Comitato per il Rispetto dei Diritti dei Neonati

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Case 1: Neonatal Cord Blood

CoRDiN Committee for the Respect of the Rights of Newborns

2014
- Law proposal asking one million Euros for the State promotion of the “cord blood donation” in 19 INHS “cord blood banks”.
- Foundation of the CoRDiN Committee at the conference on cord cutting/clamping in Rome
- Midwives Code of Ethics promotes donation

2015
- First conference at the Parliament with Adriano Zaccagnini, Member
- Scientific evidences on delayed cord clamping.
- Episteme: “NEONATAL cord blood”
- Lobbying and blocking of the Law proposal at the Senate, thanks to Senator Maurizio Romani
- Intense writing activity through D&D Italian midwives’ journal (Verena Schmid)
- Grassroots activity and conferences, field work

2016
- More conferences at the Parliament.
- Acts of obstruction by the National Blood Center
- Production of “The Blood of Its Blood” documentary
- Research studies the adherence of the national providers to the guidelines: scarce.
- Change of the cord clamping protocol in Mangiagalli hospital in Milan
- “Experts Table “ for the national guidelines on cord clamping

2017
- National Premiere of “The Blood of Its Blood”, 40 contemporary venues all over Italy
- Meeting at the National Blood Center: “You are absolutely right, but science is not democratic.”
- War on “lotus birth” by the national association of neonatologists: the hygiene hypoteses
- New guidelines on delayed cord clamping and milking: 1-3-5-go, NEONATAL cord blood, baby’s stem cells, but still donation.

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Case 1: Neonatal Cord Blood

Documentary, March 2017

National recommendations on cord clamping management, November 2017

RACCOMANDAZIONI ITALIANE PER LA GESTIONE DEL CLAMPAGGIO ED IL MILKING DEL CORDONE OMBELICALE NEL NEONATO A TERMINE E PRETERMINE.

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Osservatorio sulla Violenza Ostetrica Italia

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Case 2: Obstetric Violence


STELLA VILLARMEA, IBONE OLZA, ADELA RECIO
ON OBSTETRICAL CONTROVERSIES: REFOCALIZATION AS CONCEPTUAL INNOVATION

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Case 2: Obstetric Violence

Moving beyond disrespect and abuse: addressing the structural dimensions of obstetric violence.


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Obstetric Violence Observatory Italy (OVOItalia)

2013
- Freedom for Birth documentary
- Human Rights in Childbirth

2014
- Human Rights in Childbirth in Italy
- WHO “Prevention and elimination of disrespect and abuse during childbirth”
- Translation in Italian
- Intense advocacy with the Ministry of Health
- Hearing at the National Committee on Childbirth (MoH): Disrespect and Abuse Episteme; DATA request: “Doesn’t concern Italy”
- Babies Born Better Survey

2015
- COST Action BIRTH meeting Ibone Olza (Spain) – Obstetric Violence Episteme
- Law proposal “Norms for the Protection of the Rights of Women and Newborns in Childbirth and Regulation for the Promotion of Physiological Birth”
- COST Action STSM in UK (UCLAN): Soo Downe
- #bastatacere: mothers have voice (“#breakthesilence” international): social media campaign goes viral
- Obstetric Violence becomes public discourse
- Obstetric Violence Observatory Italy (InterOVO); QuestOVO Survey – not good for institutions
- Conference at the Parliament

2016
- Communication with the WHO
- Start working on a national opinion survey with the communication agency INC and statistics agency Doxa
- April, first national survey on obstetric violence
- September 20th, media launch of the survey outcomes
- December, communication reached 24 million people in Italy
- Legal warning letter by the national association of hospital ob-gyns
- TV interview with the parliamentary representative of the ob-gyn: let’s start a discussion table: mothers and ob-gyns.

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Case 2: Obstetric Violence

Social media campaign #bastatacere (#breakthesilence) April 4-19th, 2016
Over 1.000 testimonies, 21.000 likes, 70 spontaneous press articles in 15 days.

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Case 2: Obstetric Violence

Women and Childbirth #bastatacere
First National Survey on Obstetric Violence Doxa-OVOItalia*
Representing 5 million maternity service users in the last 14 years (2003-2017)

99%
Gave birth in a hospital
For a second pregnancy:
14% would not choose the same facility again
14% not sure if they would choose the same facility again

32%
Birth by C-section
15% emergency
14% scheduled for medical reasons
33% personal choice

Episiotomy 54%
Episiotomy “by deceit” for 1.6 million women
61% declare they did not give their informed consent
15% consider it as a genital mutilation
13% experienced it as a betrayal

21% of mothers in Italy declare they suffered obstetric violence while giving birth

≈ 1 million women in 14 years

41%
4 out of 10 women declare they were subjected to practices that violated their dignity and psychophysical integrity

33%
of mothers felt inadequately assisted (they felt excluded)

6%of women did not want any more children

20,000 children not born every year

Support the initiative! www.lagocciamagica.it

*Opinion survey (424 interviewees) conducted by Doxa in collaboration with Obstetric Violence Observatory Italy (OVOItalia), financed by La Coccia Magica and CoRDiN - Project coordinators Alessandra Battisti and Elena Skoko

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Legal warning from the national association of ob-gyn to “stop and withdraw everything”

Oggetto: inchiesta DOXA sulla “violenza ostetrica” campagna “basta tacere” Vs documentazione diffusa.

Nella mia qualità di responsabile dell’Ufficio Legale A.O.G.O.I (Associazione Ostetrici Ginecologi Ospedalieri Italiani), congiuntamente alla Presidente Nazionale e al Segretario Nazionale che mi hanno conferito mandato allo scopo e che sono firmatari di questo documento, Vi significo quanto segue.

Recentemente sono stati portati all’attenzione dell’AOGOI scritti, ed inchieste su “storie di violenza ostetrica” in Italia, con l’affermazione di essere in possesso di “dati autorevoli” su di esse. Appare evidente che già la modalità di presentazione dell’indagine, mediante l’accostamento alla parola “violenza” dell’attributo “ostetrica” ne determina un grave effetto denigratorio per i professionisti del settore. Invero le parole “violenza ostetrica”, nel momento della comunicazione, diventano già da sole e nell’immediatezza, strumento di offesa della reputazione dei professionisti sanitari, trascendendo in palese attacco e aggressione della sfera morale altrui, che certo non costituisce un generico e lecito contenuto valutativo o espressione di un giudizio rispettoso della correttezza del linguaggio e consentito dal nostro ordinamento giuridico.

La “prima ricerca nazionale realizzata dalla Doxa per conto dell’Osservatorio sulla violenza ostetrica in collaborazione con le associazioni La Goccia Magica e Ciao Lapo Onlus denuncia che il 21% delle mamme italiane con figli di 0-14 anni avrebbe subito maltrattamenti fisici o verbali durante il parto nonché azioni lesive della dignità psicofisica.

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Mothers vs Ob-gyn TV debate

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We have a political candidate:

**Alessandra Battisti**

lawyer and mother activist

Il benessere della società inizia con la buona nascita.

Partire dall’Università per diffondere il rispetto dei diritti fondamentali.

CoRDiN
Comitato per il Rispetto dei Diritti dei Neonati

Osservatorio sulla Violenza Ostetrica
Italia

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Thank you!

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