A social scientist's view of the challenges of NCDs in low and middle income countries

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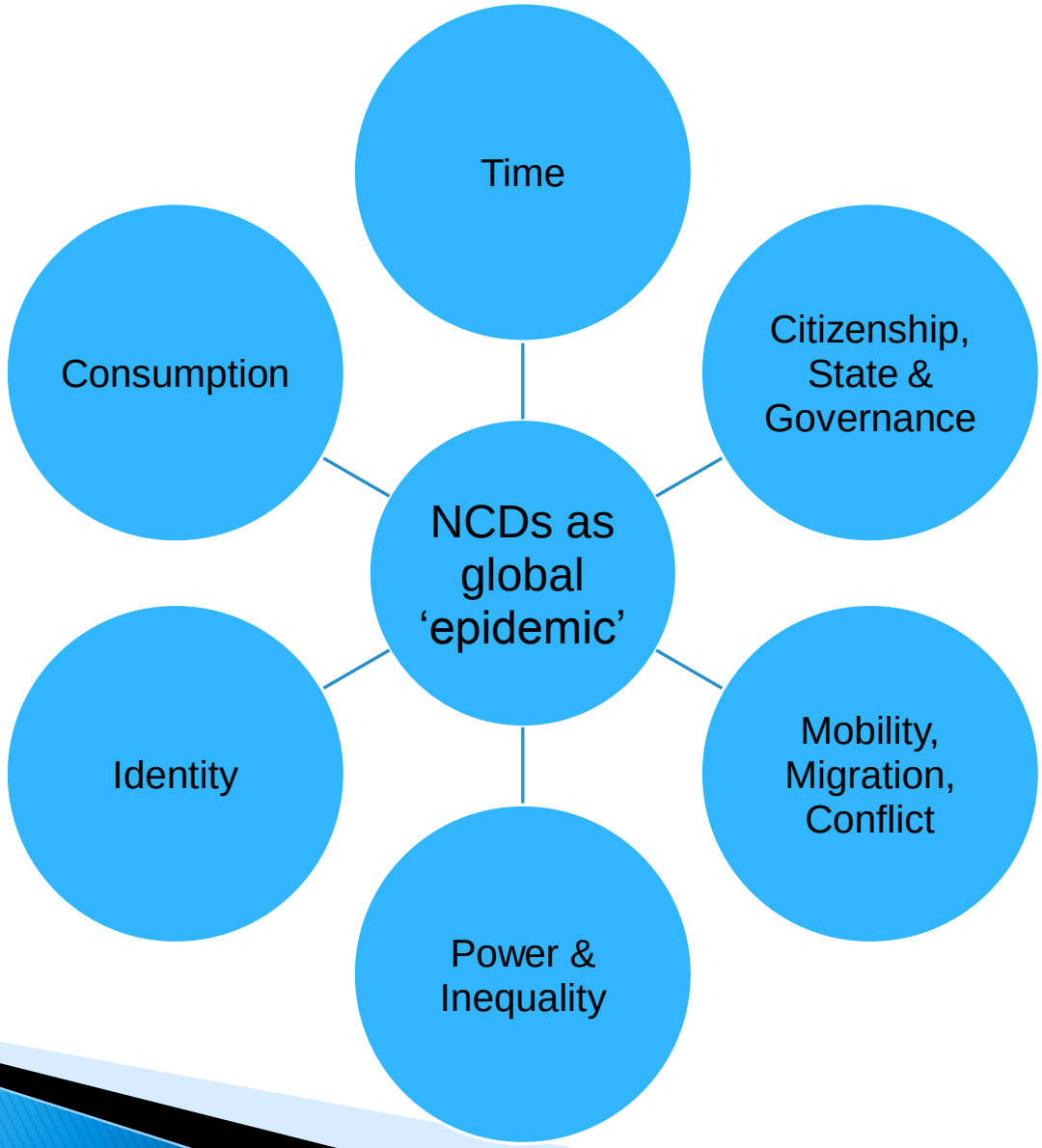
Headings

- Why the rise in NCDs requires the contribution of qualitative social science
- Scope of qualitative research on health and health systems
  - Linking popular health and the health system in one field
- Examples from MedCHAMPS
- The question of ‘culture’
- Trend towards community participation in qualitative research

A starting point: NCDs do not occur in a vacuum

Analysing NCDs leads to familiar social science topics



"Numbers alone are not enough…"

- "In the UNDP's Human Development Report 2010, five Arab countries, including Tunisia, were among the 'top 10 movers' in the past 40 years… But the Arab uprisings still started in Tunisia, which international agencies considered a 'success story'. Obviously, the people there felt otherwise. Public health as a field of study and practice is always keen to see improvements in health indicators. But, as the case of Tunisia shows, **numbers alone are not enough** and there is **a need for a broader conceptualization of health**."
  - Samer Jabbour *Bulletin World Health Org*, vol. 90(1), 2012

Mapping a broader conception of health
"What influences the influences?"

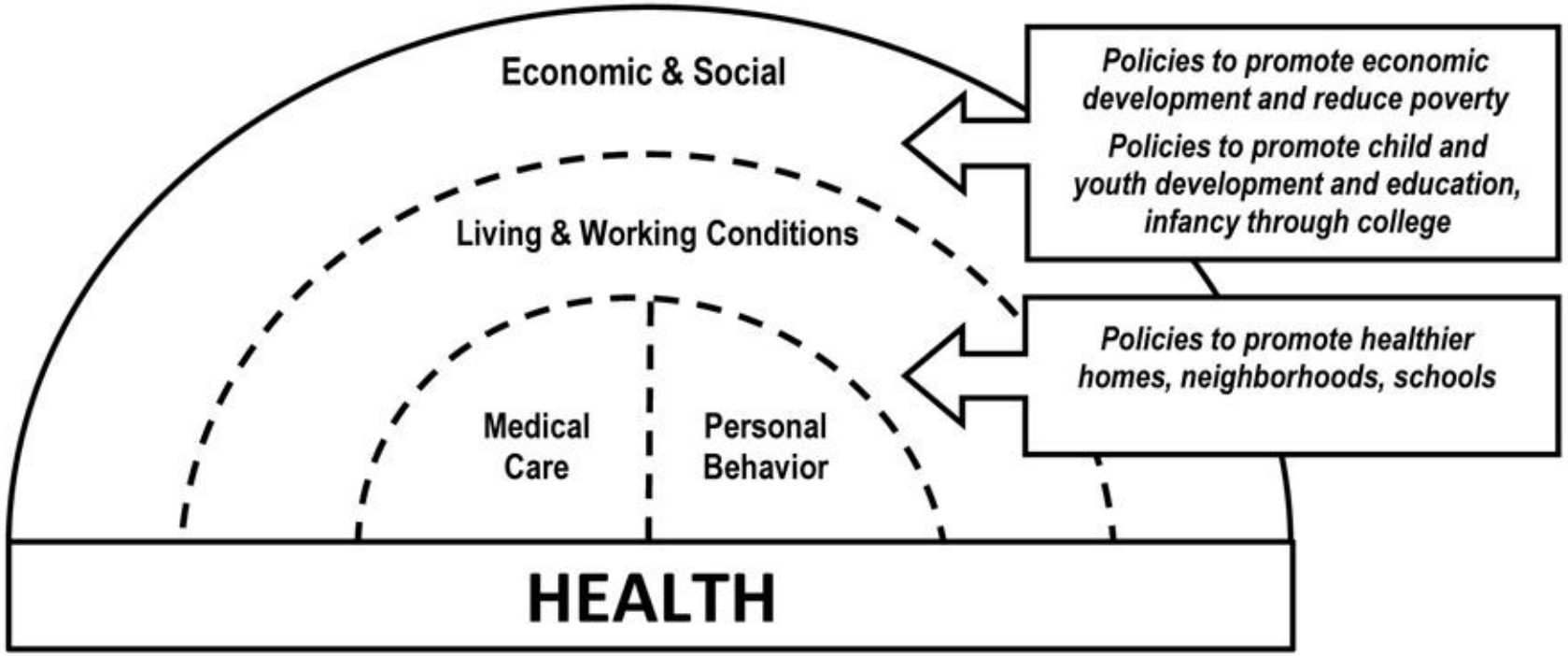


Figure 1. What modifiable factors influence health? And what influences the influences?

Source: P. Braveman and S. Egerter, *Overcoming obstacles to health: Report from the Robert Wood Johnson Foundation to the Commission to Build a Healthier America* (Princeton, NJ: Robert Wood Johnson Foundation, 2008), p. 81. Available at http://www.rwjf.org/files/research/obstaclestohealth.pdf. Copyright 2008 Robert Wood

What qualitative research offers

- **Situations in context**
  - Connections
  - Flow of events
  - Particular cases
- **The insiders' view**
  - Contrasting perspectives
  - Tacit knowledge
- **Whose views count?**
  - Who sets the agenda?
  - Power dynamics and inequality in operation

What ethnography offers in addition

- Situations in context
  - Connections
  - Flow of events
  - Particular cases
- The insiders' view
  - Contrasting perspectives
  - Tacit knowledge
- Whose views count?
  - Who sets the agenda?
  - Power dynamics and inequality in operation
- **Statements and Actions compared**
  - **Examining what people say and what they do**

Scope of qualitative research on public health
(Based on Nichter *Global Health* 2008)

- **Popular ('lay') health cultures**
  - People's beliefs about illness, the body, treatment options, cost, family priorities
- **Health system(s)**
  - Clinical practices, how clinics work, public health initiatives, policy making, agenda-setting, governance
- Emphasis on
  - Linking the two
  - Public, health professionals, planners, policy makers as **part of one field**

An ethnographic example: therapies in tension in a Cameroon hospital

- "The scene is a small rural hospital in north-west Cameroon. A few night staff remain on duty. During the evening an indigenous healer arrives, invited by members of the family of a very ill diabetic patient. Nursing staff allow him in, and he proceeds to diagnose the 'true' causes of this particular case of diabetes. The purpose of this intervention is envisaged as a way to supplement hospital care with something more powerful and effective…
- Afterwards, the healer is ushered out discreetly, and nobody present will allude to the incident in the days following. All concerned know that this is a consultation seriously breaching hospital codes of conduct, which is why it takes place surreptitiously."

  - Awah & Phillimore 'Diabetes, medicine and modernity…' (2008)

Applying these insights in MedCHAMPS
Designing a situation analysis of the health system

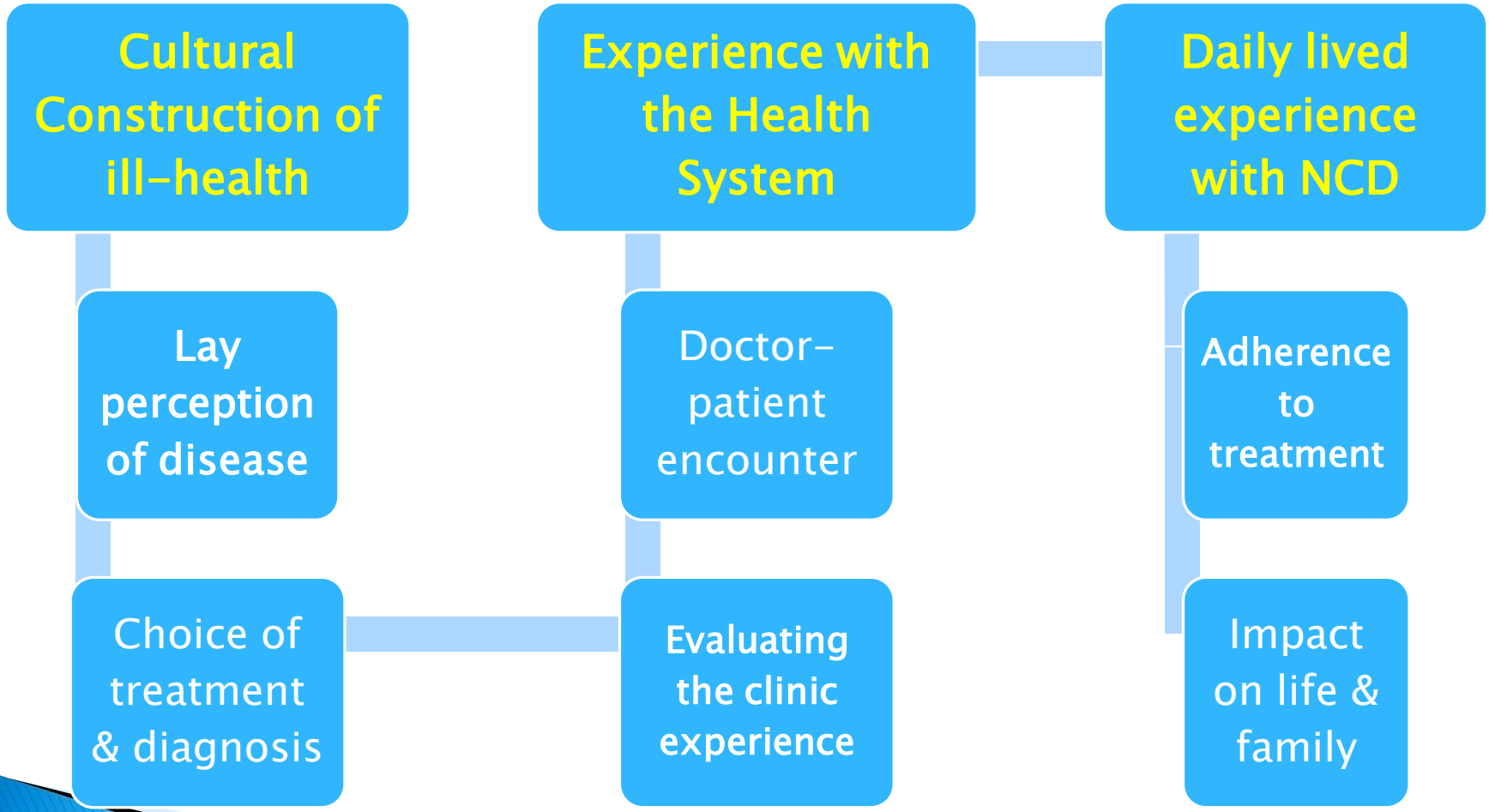
Collecting data at 3 levels in four Mediterranean countries

- **Document Analysis** of Structures and Policies
- **Key informant interviews**
- **Clinic fieldwork** (brief, in four clinics per country)
  - Public/private, urban/rural, primary/secondary

Why did we include fieldwork in clinics?

- To compare policy and actual practice
  - Pressures and dilemmas at both levels
- Because key informants speak from a privileged position
- Because there are many 'experts' on health services
  - Staff concerns
  - Patient/ public concerns

Patient pathways through diagnosis and treatment



Doing justice to local idioms and meanings
za'al

- "It's not about adhering to the right diet or to the medication or anything else.. It's the *za'al,* you can't get away from it. So no matter what you do about your food or medication, you will always have the disease, and the long term of medication makes it worse"

  [male, Palestine]

- "That was the hardest period of our lives, my husband was jobless, I had two disabled sons…*za'al* after *za'al* after *za'al*…I came to the clinic and they told me then that I have hypertension."

  [female, Palestine]

- "*Za'al* is the main cause for all of the CVD and heart attack. I have angina and hypertension because of *za'al*. During the Iraqi war, they took my husband and my four sons to prison, and I do not know what will happen to them, as they took our home…"

  [female, Syria]

Patient perceptions of public and private clinic practice

- "I sometimes visit the same doctor who treats me in the [public clinic] in his private clinic in order to show him my laboratory and X-ray results. He treats me in a completely different way."

  (Male, Syria)

  "Why are physicians so different? Why do private physicians follow you well, and the other, no, that's what I do not understand"

  (Female, Tunisia)

- "If you go to the hospital as an ordinary patient, you should be there before sunrise and you will be there till sunset."

  (Female, Turkey)

Challenges to adherence

Knowledge	Habit	Economic	Cultural Values	Infrastructure
• "When I feel that my health is good, I do not take any medication, and when I feel I am not good I will take my hypertension pills" (female, Tunisia)	• "I have been taking my medication for ten years, and I am feeling bored with all these drugs." (male, Turkey)	• "While I was in urgent need for catheterization, my family wanted to open a small grocery shop, and we lost all of our money so I had to delay it. I still don't know when I can do it. Our financial situation is going from bad to worse." (female, Syria)	• "A woman's ability to prepare Syrian specialty foods is often a measure of her competence as a homemaker. Her ability to properly set a table and make the food look appealing is a reflection of her ability as a good hostess" (female, Syria)	• 'Where would I do exercise? There is not space in my home, no public area where I can jog." (male, Palestine)

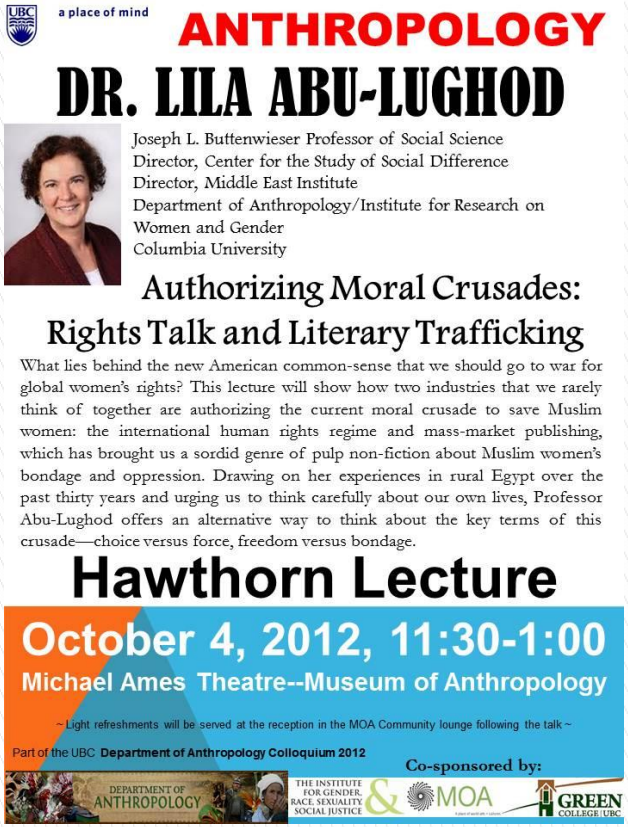
‘Culture’ and its pitfalls in health research

- There has never been more talk of culture” (Marc Augé)
- The tendency among policy-makers to highlight ‘cultural barriers’ to better health…
- BUT this depicts ‘culture’ in ways social scientists do not recognise:
  - Culture as backward (tradition, superstition, unscientific)
  - Culture as static
  - Culture as uniform (“the culture of the X”)

Lila Abu-Lughod on 'culture'
In 'Writing against culture' (1991)

"I will argue that 'culture' operates…to enforce separations that inevitably carry a sense of hierarchy… Culture is the essential tool for making other…[and] it tends to freeze differences"

(Abu-Lughod, 1991)

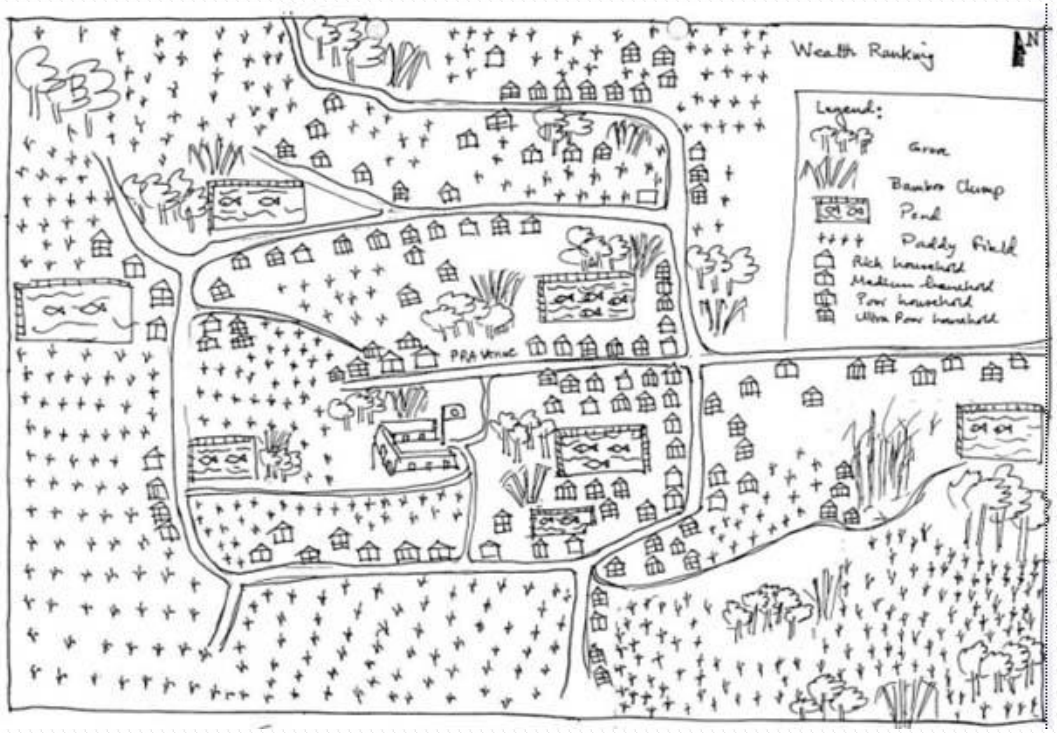


Lila Abu-Lughod is a well-known Palestinian anthropologist

Community participation in research

- The community potential for self-reflecting research
- Tapping into community knowledge through the self-awareness of local people
- The example of mHealth

For example…Participatory mapping
Engaging people in research on their own communities



- Whose maps?
- Different kinds of maps
  - By gender, age
  - what works, what doesn't
- Maps for negotiating with government about key resources or risks
  - Water
  - Clinics
  - Waste

An example from Bangladesh

Conclusion

- NCD burden is social, political and economic as much as medical
- Qualitative social science must research the health system as much as health cultures
- NCD policy making needs to recognise a more dynamic conception of ‘culture’
- The demand for, and opportunities from, engaging the public in qualitative health research on NCDs

“a need to re-evaluate the very foundations of such [health] systems” [and the need for a shift away from] “sickness systems”

Jabbour & Rawaf, *Public Health in the Arab World*

“I’ve been impressed, over the last fifteen years, with how often the somewhat conspiratorial comments of Haitian villagers have been proven to be correct when the historical record is probed carefully”

Paul Farmer, Doctor and Anthropologist