

Narrative medicine and the cultural contexts of health: an introduction

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Part 1: Introduction to narrative medicine

→ Interactive exercise

Part 2: Narrative and cultural contexts

→ Discussion

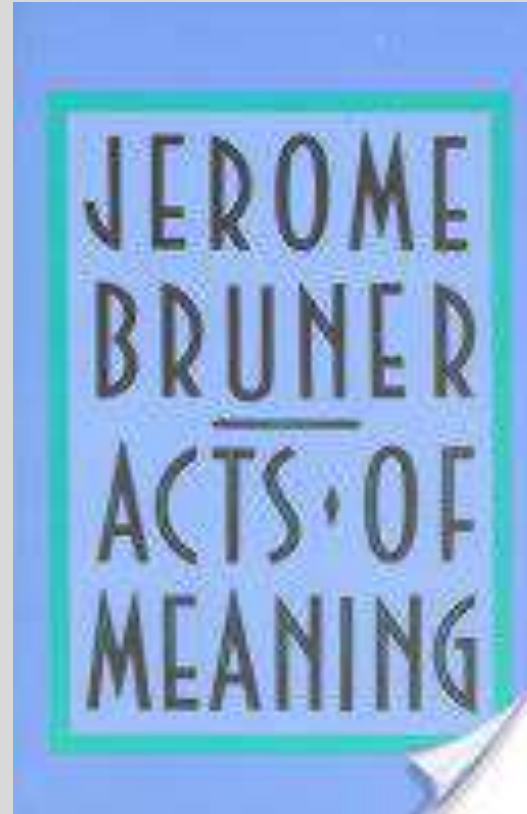
Part 1: Introduction to narrative medicine

“We dream in narrative, daydream in narrative, remember, anticipate, hope, despair, believe, doubt, plan, revise, criticise, construct, gossip, learn, hate and love by narrative.”

- Barbara Hardy

Jerome Bruner

The narrative structure
of experience; stories make
our lives meaningful



5 defining features of narrative (Aristotle)

- Chronology (unfolding over time)
- Stage or setting
- Characters (people who get into trouble)
- Trouble (a breach from the expected)
- Plot ('narrative causality' through literary devices – e.g. repetition, metaphor, suspense, surprise)

Trouble in the illness narrative e.g.

Death

Disability

Disfigurement

Distress

Pain

Loss of freedom

Stigma

Some core plots

Restitution: “I overcame my illness”

Tragedy: “My illness overcame me”

Quest: “I achieved something through my illness”

Chaos: “My illness doesn’t make sense”

- Arthur Frank

Martin Buber: I and thou (Ich und Du)

We relate to things as I-it

We relate to people inter-subjectively as I-thou – with
moral commitments and accountability

Mikhail Bakhtin: Narrative as dialogue

All stories assume an audience

Everything we say is a response to (or it anticipates) what the other person is thinking

(Sheila is telling her story *to a white British female researcher who is about the same age as her*)

What is a good illness narrative?

Aesthetic appeal (a nice story)

Coherence (the good guys win)

Authenticity (it feels real)

Reportability (the audience wants to tell it again)

Persuasiveness (the teller persuades the audience)

Explanatory value (it explains what happened and why)

Diagnostic and therapeutic value (helps the doctor's job)

Transformative value (helps the patient cope)

Narrative time is ‘event time’, not ‘calendar time’

Psychiatrist (through interpreter): “How long has your son been behaving like this”

Refugee mother: “Since he saw me raped”

“A central difficulty with clinical accounts of patient suffering is that the world of the patient is left out. This world is above all a practical and moral one in which patients have life projects and everyday concerns, things ‘at stake’.”

- Cheryl Mattingly

Sheila's story

55 years old, white British

Dying of motor neurone disease

This story-fragment describes how she can't wash her hair any more, so her husband has learnt to help her

[Sheila's story](#)

Sheila's story

“My illness has made us closer”

“I was struggling washing my hair, so my doctor arranged a social worker to help”

“My husband got very upset – said what's wrong with *me*, I can wash your hair”

“He hasn't seen me naked for years”

“He's learnt how to put shampoo and conditioner on. He's doing very well”

Interactive exercise

In a pair or small group, talk about Sheila's story

Where is the 'trouble' and how is it resolved?

What is the 'plot'? In what way is it morally coherent?

Consider the I-thou relationship and the husband's ethical commitment and accountability to Sheila

Why does Sheila tell her story in this way to this audience?

What does the story tell us about the cultural context of health?

Part 2: Narrative and cultural contexts

HEALTH EVIDENCE NETWORK SYNTHESIS REPORT 49

**Cultural contexts of health: the use of narrative research
in the health sector**

Trisha Greenhalgh

Major initiative by World Health Organisation to include narrative research as evidence about the cultural contexts of health

Example of narrative research into cultural contexts

The GIFTS research programme 2011-16

PI Professor Graham Hitman

- EU funded (FP7): €3 million
- Goal: *To explain why South Asian women often have children who go on to develop type 2 diabetes at a young age*
- Combined genetics + RCTs + qualitative studies
- Work package 9 = storytelling (€45K)

The problem

South Asian women often gain weight in pregnancy

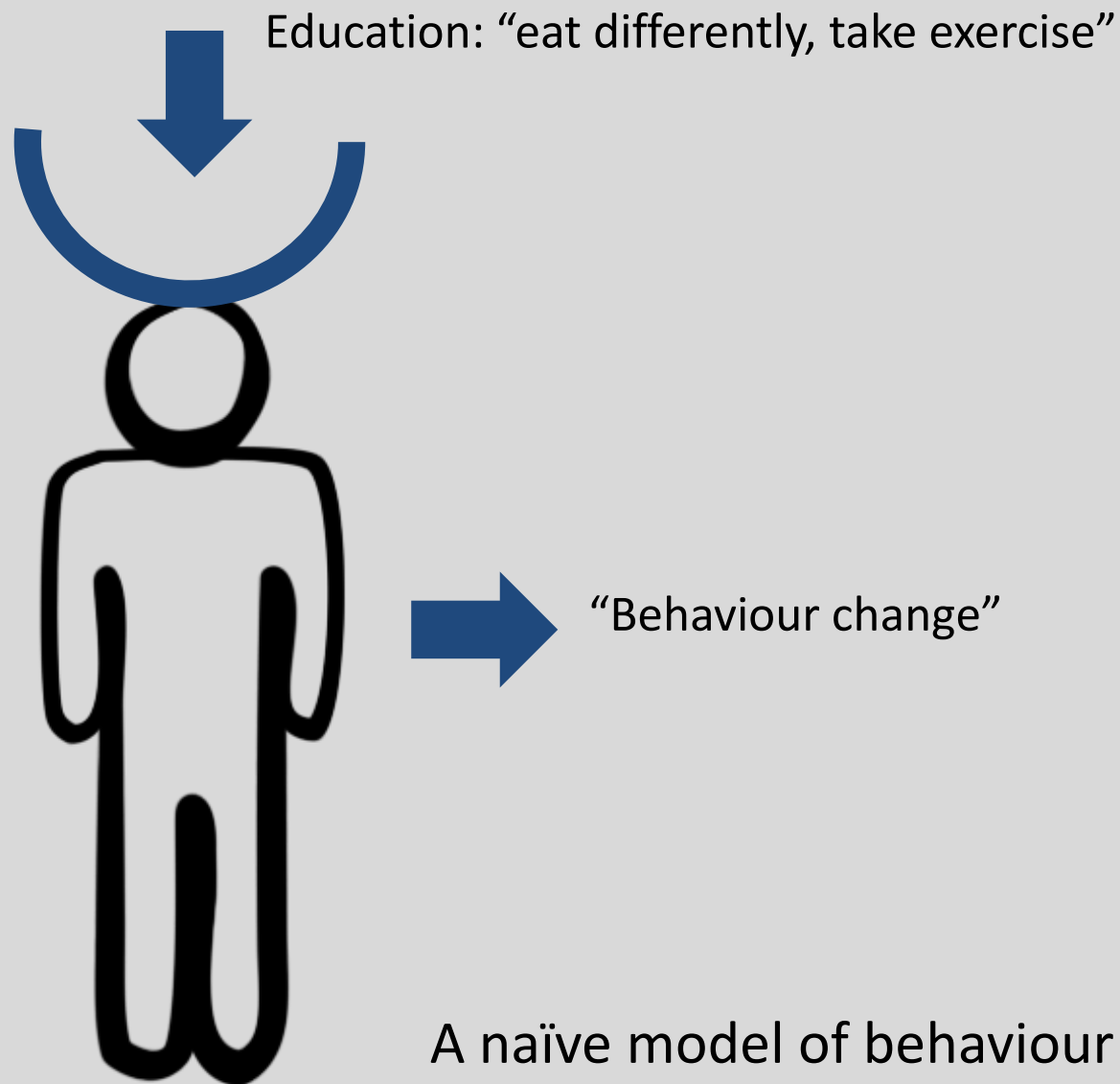
They are at high risk of type 2 diabetes

Many have gestational diabetes

The children of South Asian diabetic mothers have very high risk of developing type 2 diabetes

This is partly genetic and partly because

- South Asian women don't take much exercise during pregnancy
- They eat more than they need during pregnancy



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RESEARCH ARTICLE

Open Access

Socio-cultural influences on the behaviour of South Asian women with diabetes in pregnancy: qualitative study using a multi-level theoretical approach

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Abstract

Background: Diabetes in pregnancy is common in South Asians, especially those from low-income backgrounds, and leads to short-term morbidity and longer-term metabolic programming in mother and offspring. We sought to understand the multiple influences on behaviour (hence risks to metabolic health) of South Asian mothers and their

GIFTS storytelling study: aims

1. To understand the multiple influences on behaviour (hence, the risks to metabolic health) of a South Asian mother and her unborn child;
2. To theorise how these influences interact and build over time; and
3. To inform the design of culturally congruent, multi-level interventions.

GIFTS storytelling study: design

- 45 South Asian women with current or past pregnancy complicated by diabetes (gestational or pre-existing)
- Story-sharing groups OR individual interviews
- Interviewed in own language by multilingual researcher
- Conversational approach: “Tell the story of your diabetes”
- Narrative prompts: “Tell more”, “Tell why you felt like that” etc
- Audiotaped, translated/transcribed, analysed as stories

Results: what were the stories about?

Short-term (stories about a current or recent pregnancy)

- Pregnancy with diabetes as a stressful, out-of-control state
- Impact of behaviour on symptoms, especially ‘exercise makes me ill’ and ‘I feel better when I eat for two’
- Accounts of advice, especially from other women

“A lot of people advised me to eat this or eat that for your diabetes so I followed their orders rather than just the doctors”

Results: what were the stories about?

Medium-term (stories about family life, community life, past healthcare encounters)

- Stories of domestic life, especially ‘a woman’s work is never done’
- Stories of progressive weight gain
- Past experiences with illness and/or health services e.g. ‘when I went to the doctor I was told my illness was not important’

“all I’ve become is a waste bin”

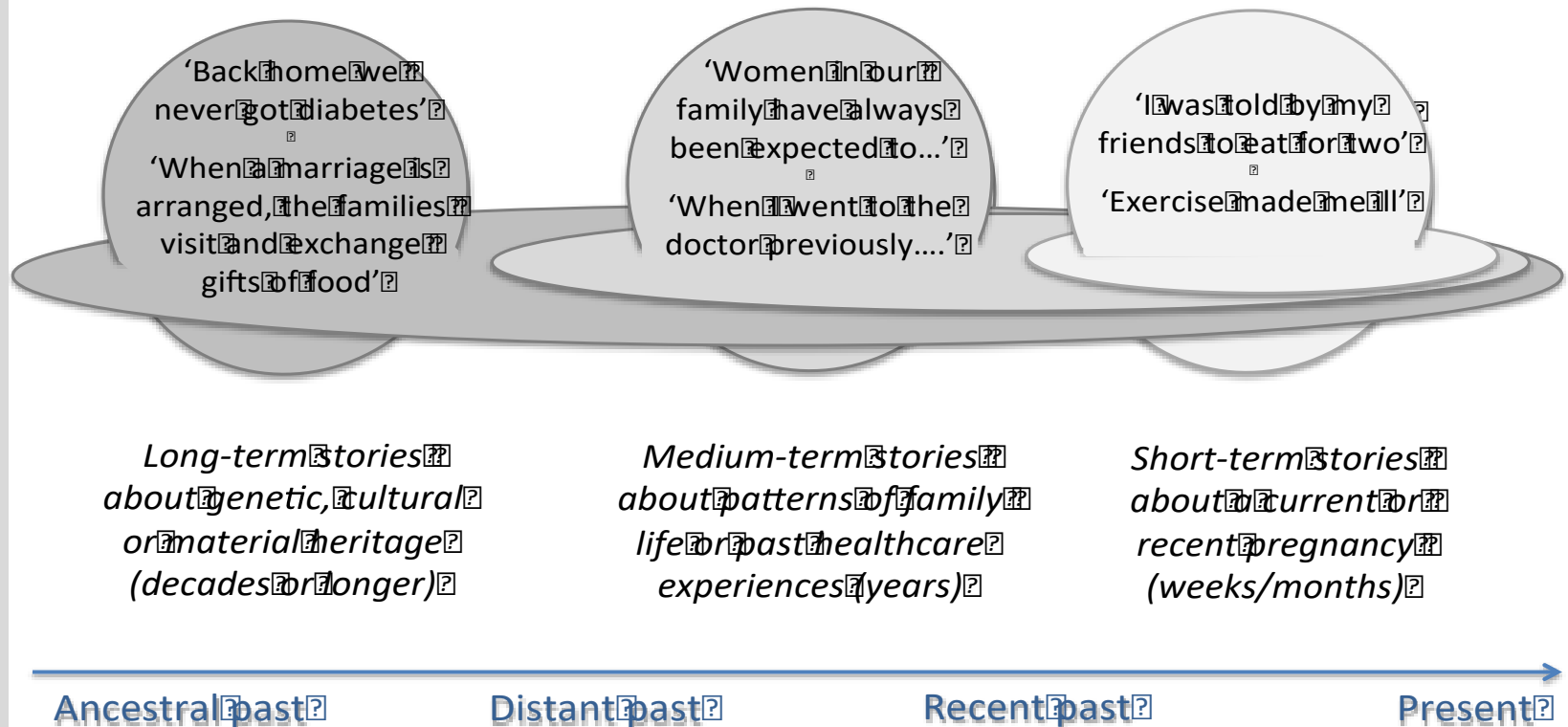
Results: what were the stories about?

Long-term (stories about the distant past)

- Genetic heritage e.g. strong family history
- Cultural heritage e.g. subservience of the individual to family/community
- Material heritage e.g. food insecurity, 74/75 famine in Bangladesh

“back home the life was much healthier, we never got diabetes”

Results: how did the stories link up?



Example: A fictionalized narrative

Fatima is 31. She came to the UK from Bangladesh at 16 and married at 17. She had five children – three girls and then two boys. Her last child, born 3 years ago, was stillborn at 36 weeks. All her children weighed more than 3.5 Kg. Her elder son, delivered by forceps, spent three days in the special care unit when he was born. Fatima's eldest daughter Ratna is now 13 and is teased at school for being overweight.

Fatima says she did not have diabetes with her first three pregnancies (though she's not sure if she was tested). She was diagnosed with gestational diabetes at 24 weeks in the last two pregnancies. She was terrified when told this diagnosis, fearing that the unborn baby would be damaged or die. She was told to cut down her rice intake, avoid sugar and sweet foods, and use less oil. **She tried hard to follow this advice, but the diet made her feel very weak and her female friends and relatives told her she must take sufficient rice to maintain her strength and nourish the baby.**

Example: A fictionalized narrative

In her last two pregnancies, Fatima monitored her sugar levels by pricking her finger several times a day. She attended the hospital clinic every week, taking her younger children with her on the bus. The staff were very nice but the clinic was busy and waiting was stressful. Later in each pregnancy, Fatima was put on insulin injections, which she hated as they were painful. She persevered because she feared for her child's life. Her father, who lived nearby, was able to help and support her with the insulin injections because he too was taking insulin. But Fatima felt that her dad's diabetes was easy to control compared to her own, which seemed to fluctuate unpredictably.

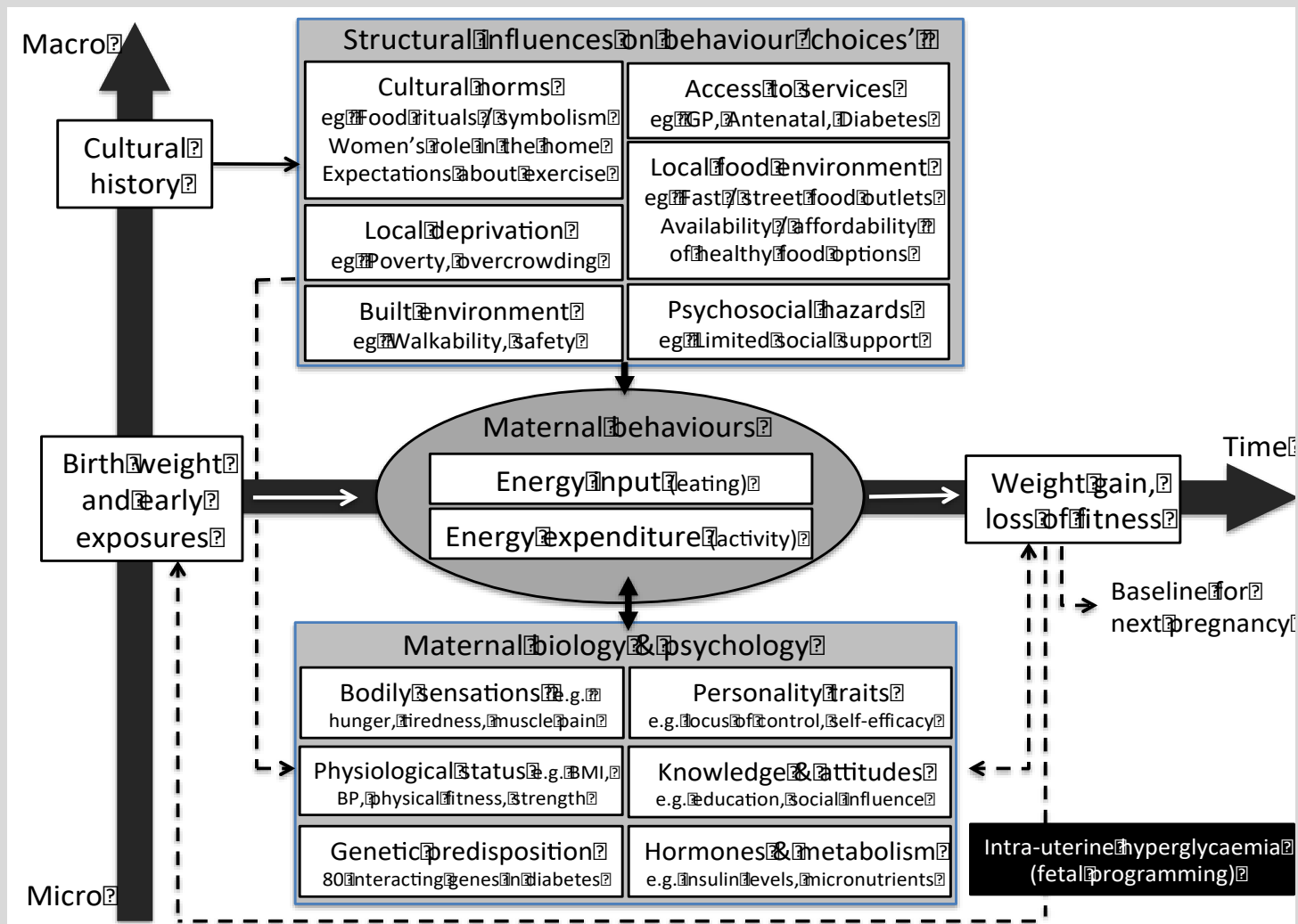
Fatima felt very tired, and her feet swelled up, especially during her last two pregnancies. Her regular domestic duties (housework, cooking, taking the children to and from school) took many hours and were physically demanding, as was her five times daily prayer ritual. She was sure all this exercising made the tiredness much worse, so she tried to rest up as much as possible between her chores. In any case, she didn't feel safe exercising outdoors in the evenings in this part of town.

Example: A fictionalized narrative

In each of her pregnancies, Fatima put on weight, which she thought was due mainly to fluid. She lost some but not all of this weight after the baby was born – perhaps partly because she found herself finishing up leftovers (her family can't afford to throw food away). **Her mother and sister had had a similar pattern of progressive weight gain with each of their pregnancies, so she felt this was probably normal.**

Thankfully, a blood test six weeks after the birth of each of Fatima's sons showed that her diabetes had gone away. She was glad she didn't have it any more and that she could eat normally with the family again. She was very surprised a few months ago when her tiredness returned and her GP diagnosed type 2 diabetes. She can't understand this, since she never took sugar in her tea after attending the diabetes education sessions when she was pregnant, and she uses less oil in cooking than most of her friends. The GP told her she must go back on the strict diet, take tablets, and take more exercise – otherwise she might get complications. But with four children and elderly in-laws to look after at home, she has very little time to attend to her own health.

Summary: A nested hierarchy of influences



Conclusion

1. Pregnancy-related behaviours (prompted by peers), were *intimate* (deeply personal), *familiar* (grounded in the richness of family relationships and traditions), and *morally resonant* (viewed as the right thing to do).
2. Didactic education (telling women to change their behaviour) will be ineffective.
3. We must make health advice more culturally meaningful and more morally resonant.

DISCUSSION

Thank you for your attention

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