

**The Adverse Childhood
Experiences (ACE) Study
and its implications for the
study of illness narrative**

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Origins of the ACE Study

- **1980-85 Dr Vincent Felitti, a specialist in preventive medicine at Kaiser Permanente offered a programme in supplemented fasting to Kaiser enrollees weighing more than 135 Kilos.**

Key finding of dieting programme

- **Patients who lost weight were the ones most likely to withdraw from the programme**
- **Felitti did follow up interviews with 286 patients who had dropped out of the weight loss programme.**

Some striking interview responses

- **What did you weigh when you first became sexually active?**
- **40 lb (18 Kg)**
- **‘Overweight is overlooked, and that’s the way I need to be.’ Obesity wasn’t a problem, it was the solution. She had very good psychological reasons for not wanting to lose too much weight.**

ACE Study Design

Survey Wave 1 -- complete
71% response (9,508/13,454)
n=15,000

71% response

*All medical evaluations
abstracted*

vs.



Survey Wave II
n=15,000

*All medical evaluations
abstracted*

Mortality

National Death Index

Morbidity

Hospital Discharge

Outpatient Visits

Emergency Room Visits

Pharmacy Utilization

The Adverse Childhood Experiences (ACE) Study

1. Emotional abuse: recurrent threats, humiliation (11%)
2. Physical abuse: beating (28%)
3. Sexual abuse (28% women, 16% men, 22% overall)
4. Mother treated violently (13%)
5. Household member was an alcoholic or a drug user (27%)
6. Household member was imprisoned (6%)
7. Household member was chronically depressed, suicidal, mentally ill or in psychiatric hospital (17%)
8. Not raised by both biological parents (23%)

ACE Score

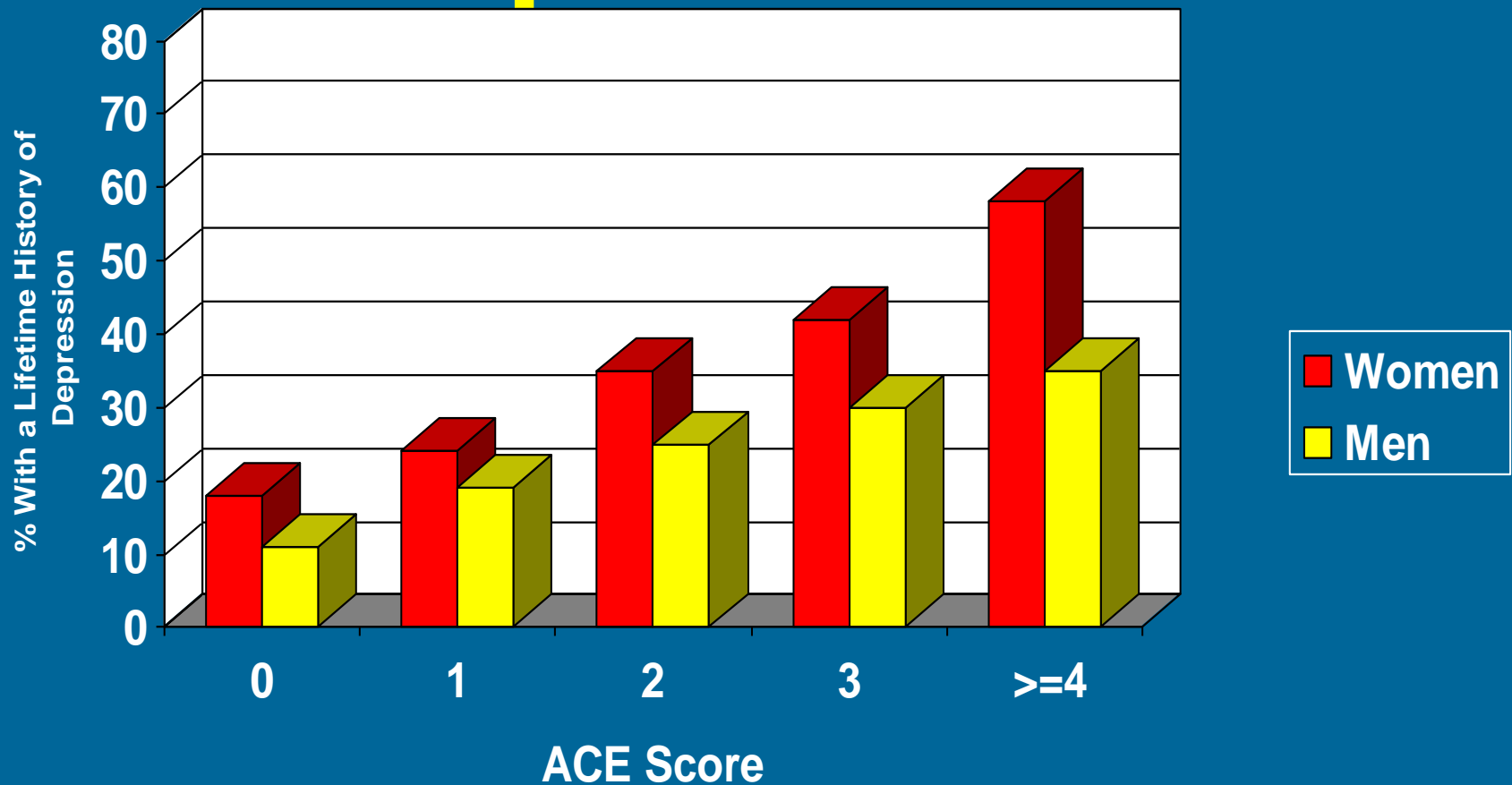
Number of categories adverse childhood experiences are summed ...

<i>ACE score</i>	<i>Prevalence</i>
0	31%
1	25%
2	13%
3	17%
4 or more	14%

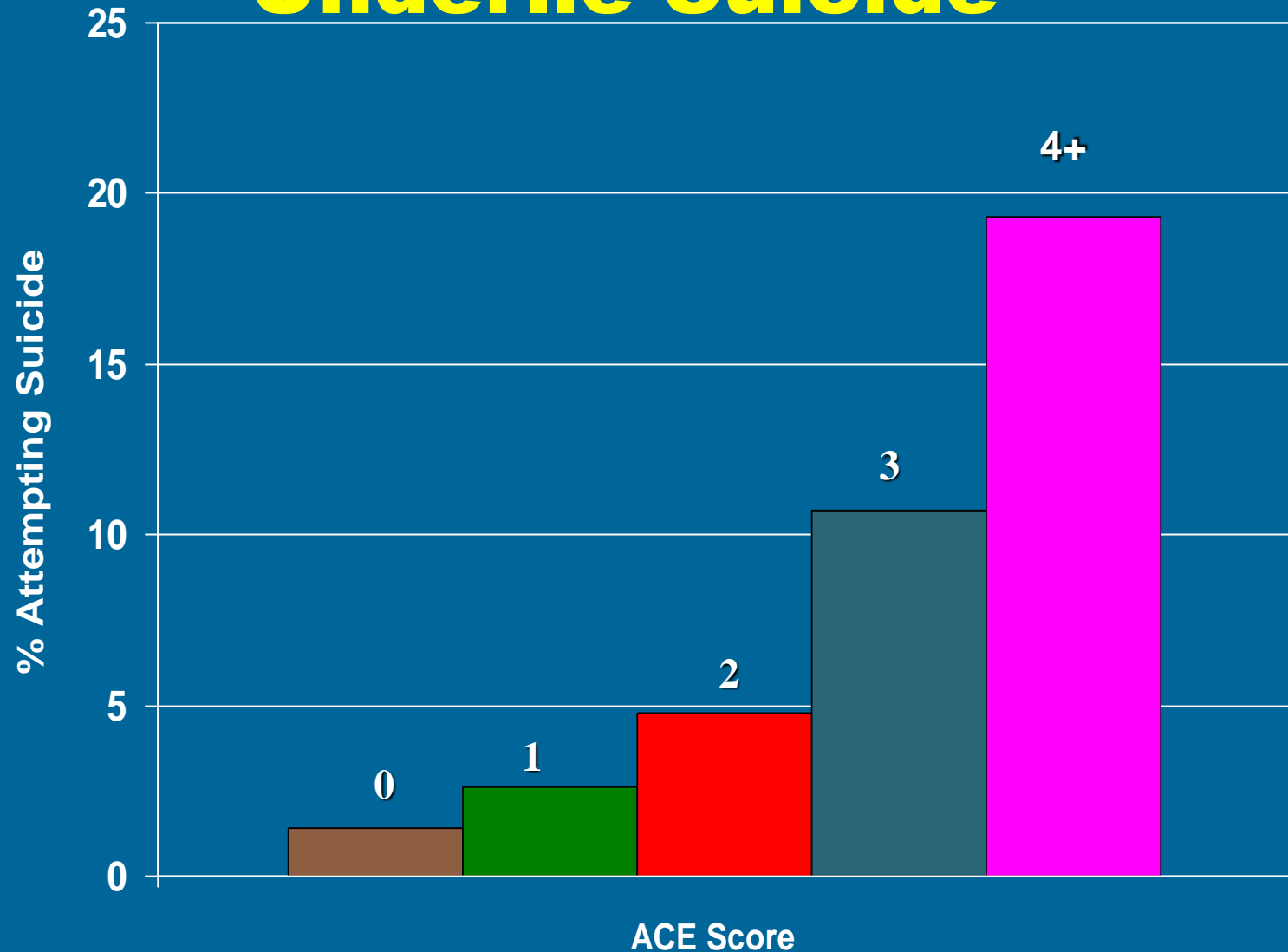


- More than *half* have at least one ACE
- If one ACE is present, the ACE Score is likely to range from 2.4 to 4

Childhood Experiences Underlie Chronic Depression



Childhood Experiences Underlie Suicide

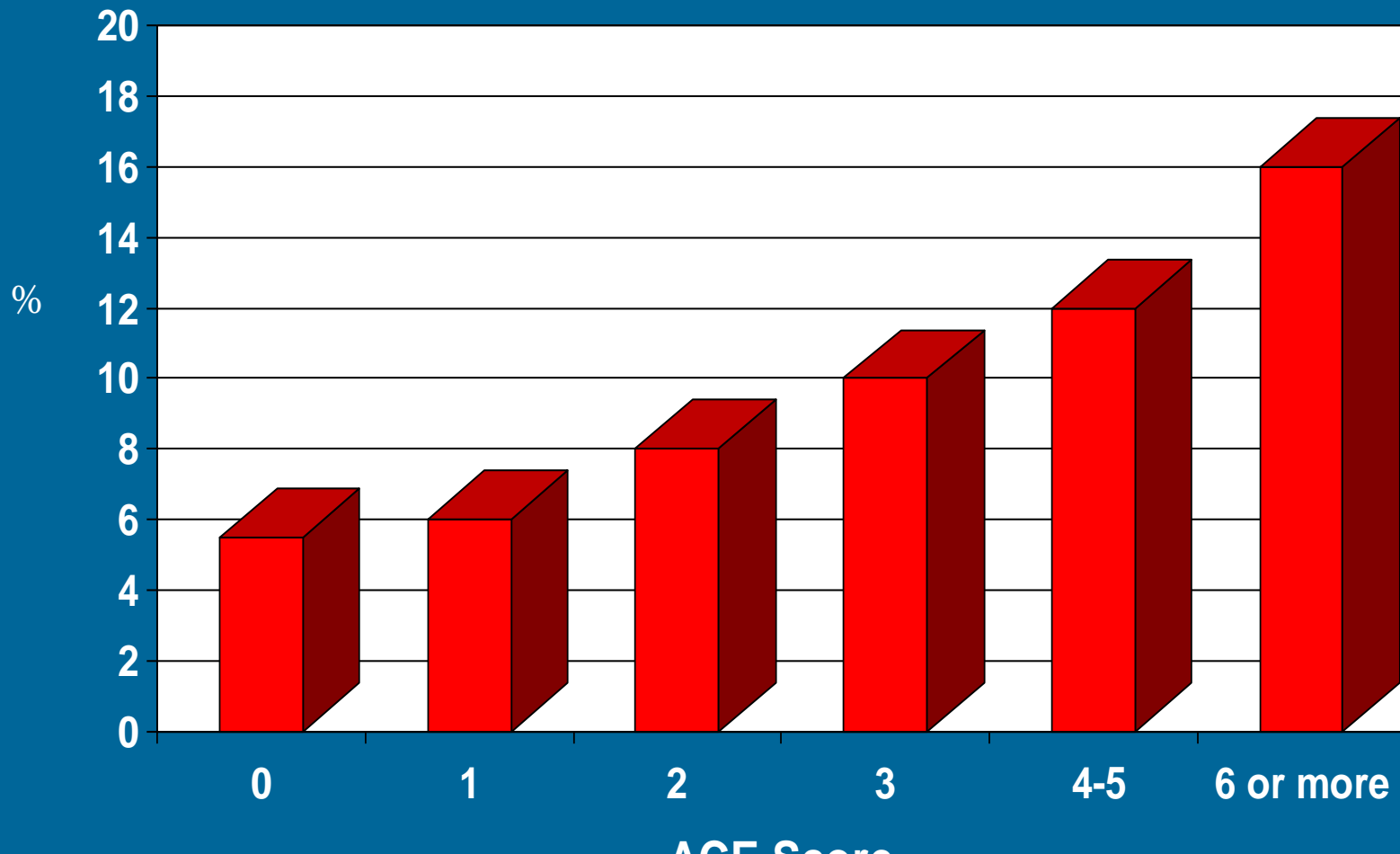


Estimates of the Population Attributable Risk* of ACEs for Selected Outcomes in Women

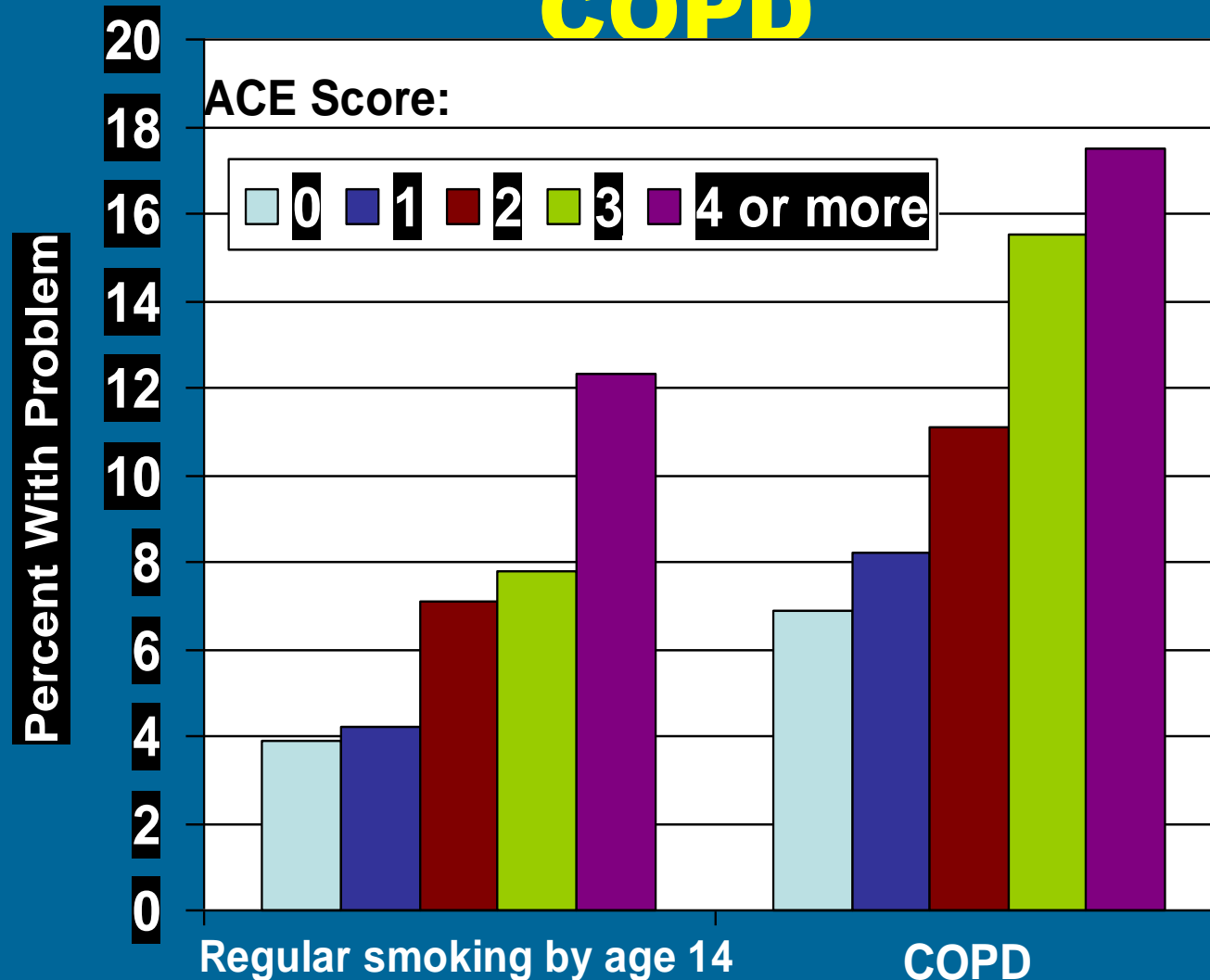
Mental Health	PAR
Current depression	54%
Chronic depression	41%
Suicide attempt	58%

*That portion of a condition attributable to specific risk factors

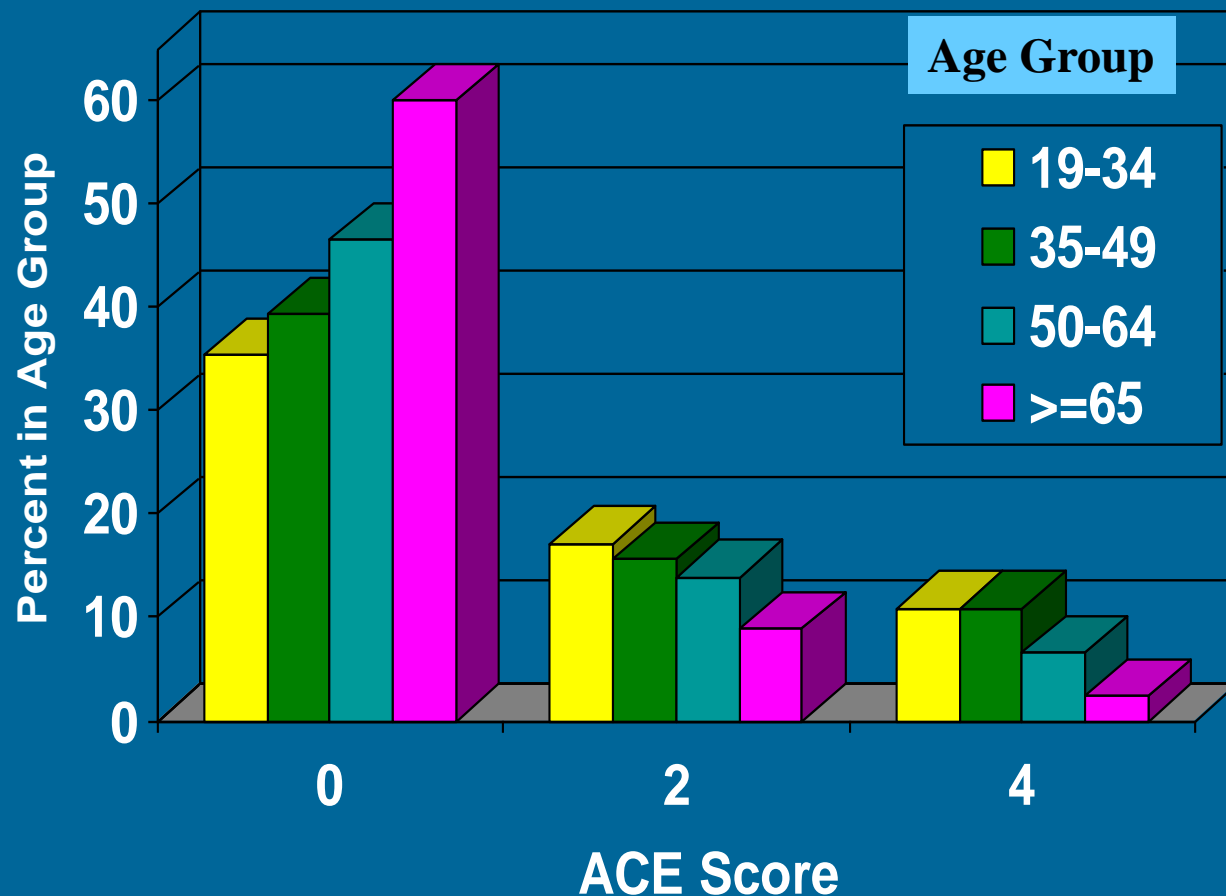
Adverse Childhood Experiences vs. Current Smoking



ACE Score vs. Smoking and COPD



Effect of ACEs on Mortality

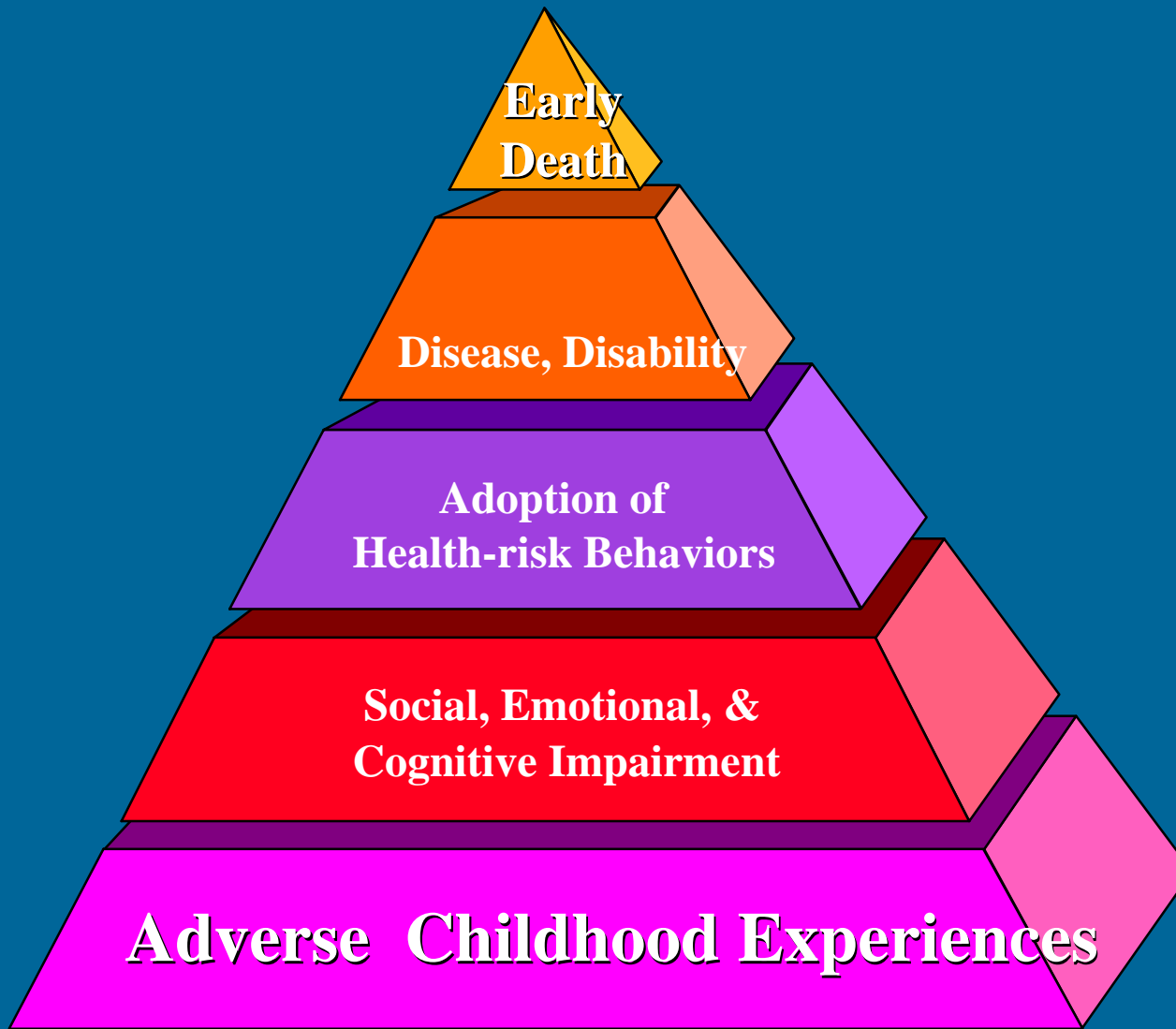


Evidence from ACE Study Suggests:

Adverse childhood experiences are the most basic cause of health risk behaviors, morbidity, disability, mortality, and healthcare costs.

Death

Birth



The Influence of Adverse Childhood Experiences Throughout Life

What is the significance of the ACE study for the study of illness narrative?

Illness narrative adopts a whole life perspective;

It reveals the dynamic interaction of biological, psychological and social factors;

It often emphasises childhood adversity

Example 1: Hilary Mantel, *Giving Up the Ghost* (2003)

Describes a very unusual childhood in which a little girl becomes chronically sick with minor, non-specific ailments. It is hinted that being ill was the only means at her disposal of getting her mother to take her wishes into account. Her GP called her 'Little Miss Neverwell.'

Example 1: Hilary Mantel, *Giving Up the Ghost* (2003)

Aged 18, Mantel is assailed by diffuse, severe pains (probably prodromal signs of endometriosis). Her doctors tell her these are hysterical. She is admitted to a psychiatric ward where she has an akathisia reaction to antipsychotic medication. She leaves the hospital.

Example 1: Hilary Mantel's *Giving Up the Ghost* (2003)

**What was Hilary Mantel's
ACE score?**

The Adverse Childhood Experiences (ACE) Study

1. Emotional abuse: recurrent threats, humiliation (11%) ✓
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5. Household member was an alcoholic or a drug user (27%)
6. Household member was imprisoned (6%)
7. Household member was chronically depressed, suicidal, mentally ill or in psychiatric hospital (17%) ✓
8. Not raised by both biological parents (23%) ✓

Hilary Mantel's ACE score was at least 3.

If Mantel hadn't been subject to so much distress as a child she would not have become sickly and neither would she have learned to tolerate so much bodily discomfort. She feared her mother's waywardness very much. The sick role gave her a degree of authority over her. She knew no other way of securing her mother's concern. But this eventually proved to be her undoing because when she became physically unwell with endometriosis her doctors said she was mad. Her willingness to endure her pains prevented a timely diagnosis.

Example 2: Lucy Grealy, *Autobiography of a Face* (2000)

Describes a very unusual childhood in which a little girl is diagnosed with a rare form of facial cancer.

She has multiple reconstructive surgical procedures, many of which fail.

Her parents struggle to pay medical bills. Father dies, mother severely depressed.

Example : Lucy Grealy's Autobiography
of a Face

**What was Lucy Grealy's ACE
score?**

The Adverse Childhood Experiences (ACE) Study

1. Emotional abuse: recurrent threats, humiliation (11%) ✓
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6. Household member was imprisoned (6%)
7. Household member was chronically depressed, suicidal, mentally ill or in psychiatric hospital (17%) ✓
8. Not raised by both biological parents (23%) ✓

Lucy Grealy's ACE score was at least 5.

Example 2: Lucy Grealy, *Autobiography of a Face* (2000)

If Grealy hadn't learned to believe that her illness was responsible for her mother's depression and her father's early death, and if she hadn't suffered so much early life trauma at the hands of other children, she might not have become so reliant on prescription painkillers and opiates. She died of a heroin overdose in 2002.

Conclusion 1

Illness narrative is a rich source of information about the damaging effects of adverse childhood events.

It reaches beyond statistical correlation to reveal the dynamic links between the biological, the social and the psychological aspects of illness.

Physicians should read illness narratives as a 'thick description' (Geertz) of the correlations reported in longitudinal epidemiological studies of disease.

Conclusion 2

Diseases invade a lifeworld (Husserl). They cause reorganisations in behaviour and outlook that change the way one approaches life. These changes can themselves exacerbate unfolding pathological processes and expose sufferers and their families to more illness. Illness narratives offer retrospective accounts of *some* of the ways in which these things occur.