

Inequities in End of Life

Yukiko Asada, Ph.D.



**Department of Community Health
and Epidemiology**

From inequities in health to inequities in end of life

- A framework for measuring health inequity
 - Why are we morally concerned about health inequalities, and how do we measure them?
 - Marrying ethics and quantitative methods
 - *Journal of Epidemiology and Community Health* (2005) 59:700-705
 - *Health Inequality: Morality and Measurement* University of Toronto Press (forthcoming)

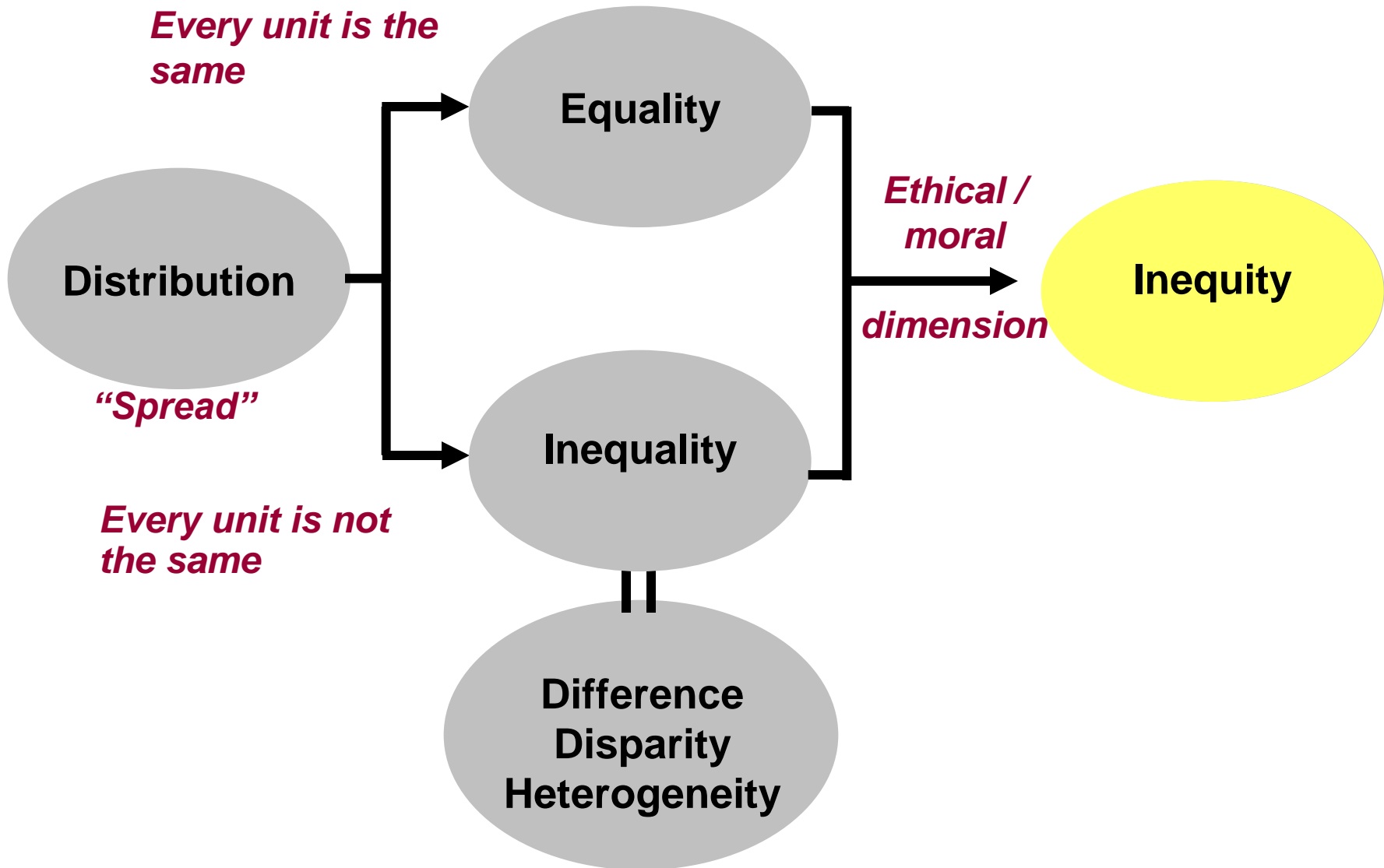
- Network for End of Life Studies (NELS)
 - Defining inequities in end of life
 - Measuring inequities in end of life
 - Defining vulnerable populations at the end of life

Purpose of today's talk

- To share:
 - my previous work on defining inequities in health
 - my initial thoughts on defining inequities in end of life

Terminology

Suppose you select a good (e.g., health, income), a population (e.g., country, county), and unit of analysis (individual or group)...



Inequality is everywhere...

- ❑ Some inequalities we do not care
- ❑ Other inequalities we do care
 - Some inequalities we are worried about
 - Other inequalities we celebrate
 - Yet other inequalities we are not sure

What kind of inequality is *health* inequality?

Our interests in health inequality

- We are interested in health inequality because:
 - we want to describe how health is distributed
 - we want to analyze “why some are healthy while others not”
 - some health inequalities are *of moral concern*

Moral concerns and measurement

- ❑ If we are interested in health inequality for moral reasons, they should be reflected in measurement

- ❑ A framework for measuring health inequality sensitive to moral concerns is yet to be developed:
 - Philosophy: lack of attention to health
 - Bioethics: lack of interest in population health ethics
 - Health: no conceptual underpinning beyond intuitive appeal

Which health distribution is inequitable?

Strict equality of health outcome

□ Rationale

- Health is special like political liberty
- Health is a particularly important welfare component and a multi-purpose resource

□ Problems

- Chance
- Cost
- Choice

Strict equality of health outcome is not an attractive equity perspective

Two ways to “relax” strict equality of health outcome

- Focusing on cause
 - Health inequality caused by certain factors are inequitable
- Focusing on level
 - Whatever the cause of health inequality is, when health is below a threshold it is inequitable

Focusing on cause

- ❑ To determine which health inequality is inequitable, we will examine what causes health inequality
- ❑ Health determinants in moral investigation of health inequality
 - Individual choice (e.g., skydiving)
 - Failing of social responsibility (e.g., health care)
 - Nobody's fault (e.g., natural disaster)

Focusing on cause

- Health inequality associated with the following factors are inequitable:
 - Socioeconomic status (SES)
 - Expansion of Rawls's theory of justice
 - Walzer's complex equality
 - Factors beyond individual control (Whitehead, LeGland)
 - Factors amenable to human interventions (WHO)

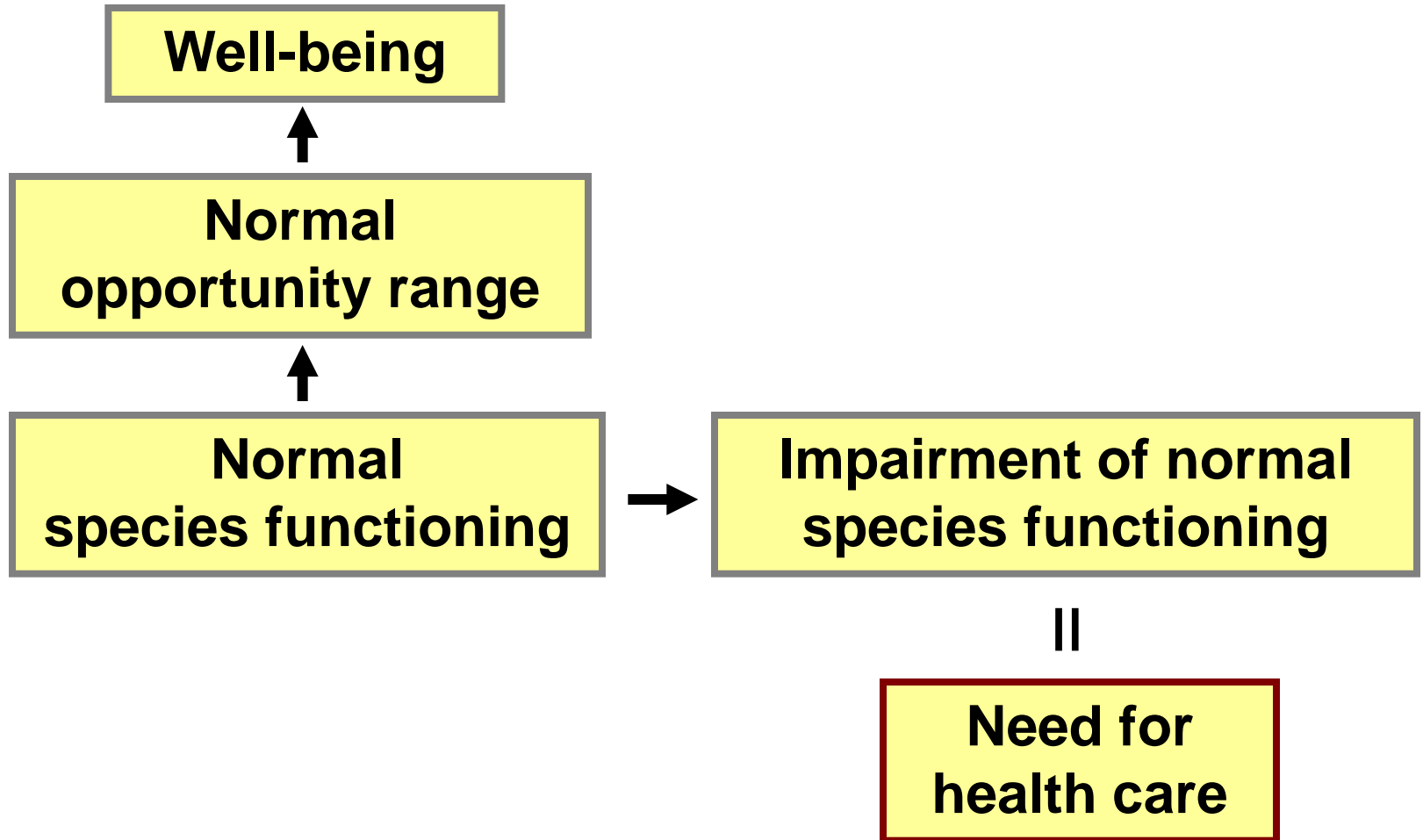
How do different perspectives judge different health inequalities?

Health inequality caused by	Perspective		
	SES	Beyond individual control	Amenable to human interventions
SES	X	X	X
Skydiving			X
Random genetic disease		X	X
Sex		X	
Gender	X	X	X

Focusing on level

- ❑ No interests in causes of health inequality
- ❑ What is important is satisfying the “minimally adequate level of health”
 - Normal Species Functioning (Daniels)
 - Capability Approach (Nussbaum and Sen)

Normal species functioning



Health inequality as a general indicator of social justice

- ❑ Health is an ultimate outcome of basic social organizations
- ❑ Health inequality may be able to tell how society fares in terms of justice
- ❑ Sen (1998), Daniels, Kennedy, and Kawachi (2000)

Perspectives on health inequity (summary)

- ❑ Strict equality of health outcome
- ❑ Health inequality caused by:
 - SES
 - Factors beyond individual control
 - Factors amenable to human interventions
- ❑ Health equality as satisfying the minimally adequate level of health
- ❑ Health inequality as an indicator of general social justice

Defining inequities in end of life

Thinking path

- ❑ What kind of good is end of life in the space of equity?
- ❑ Can different perspectives on health equity applied to end of life?

End of life and end of life care

- ❑ At the end of life the importance of end of life care as a determinant of health (or death) is very pronounced
- ❑ What people value at the end of life is not merely good health (as best as possible) but things like:
 - Sense of control
 - Dignity, respect
 - Time to reflect
 - Time with family members
 - Sense of closure

End of life and end of life care (continued)

- ❑ End of life and end of life care should be thought together when thinking about equity
- ❑ Consideration for end of life should include non-health issues, such as sense of control, dignity, friendship, etc.

End of life care

- Availability
 - Uptake
 - Quality
- (Hausman)



“Good death” (Kehl 2006)

- In control
- Comfortable
- Sense of closure
- Affirmation/value of dying person recognized
- Trust in care providers
- Recognition of impending death
- Beliefs and values honored
- Burden minimized
- Relationships optimized
- Appropriateness of death
- Leaving a legacy
- Family care

Two complimentary perspectives on equity in end of life (1)

- Assuming that providing basic end of life care is not too expensive, decent end of life care and death are something everybody should have
 - Parallel to the minimally adequate level of health view (i.e., focusing on level)
 - Recognizing “essential vulnerability” (O’Neil)
 - Leading to universal treatments

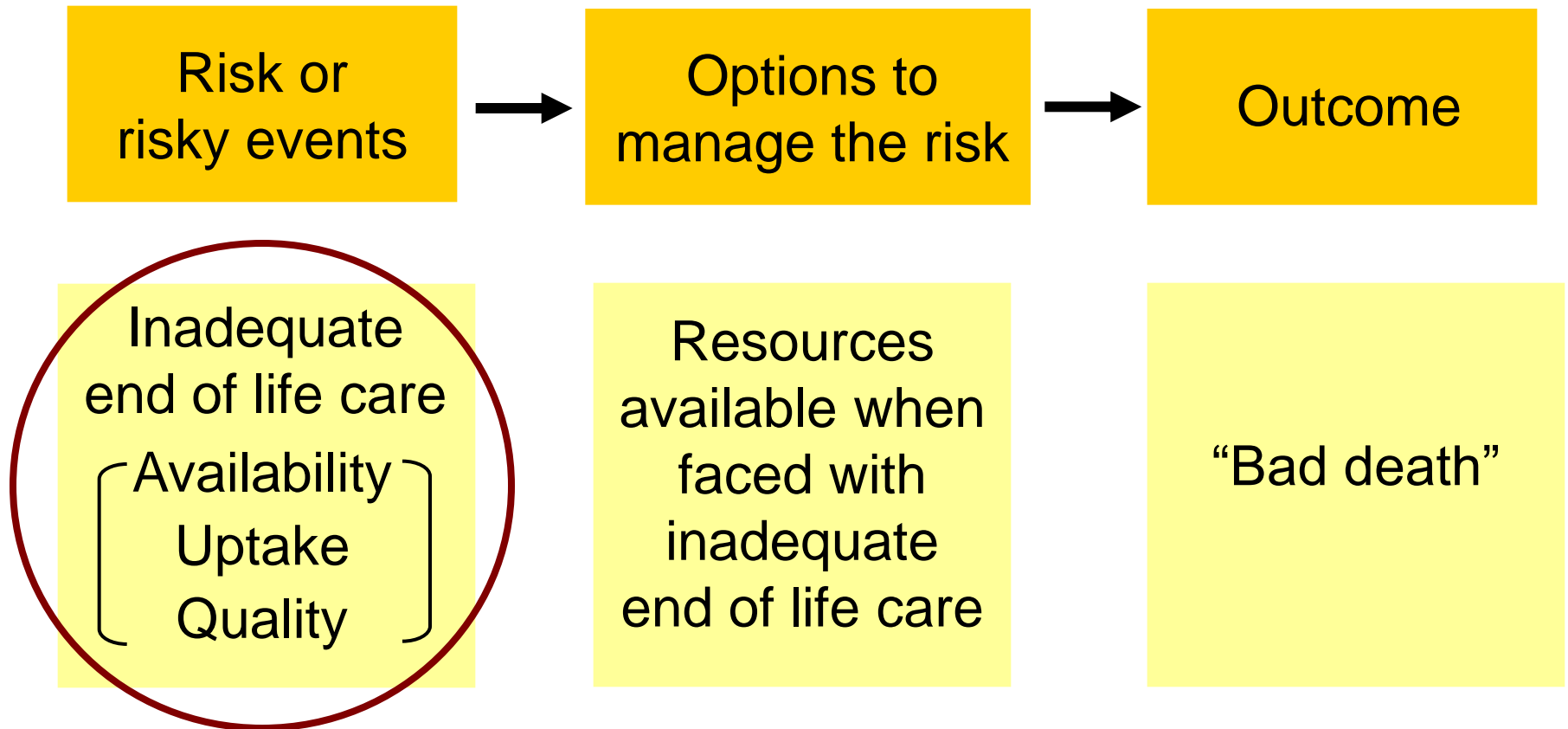
Two complimentary perspectives on equity in end of life (2)

- While trying to provide decent end of life care and death to everyone, we should also attend to those who are likely to fail to have them
 - Parallel to health inequity as health inequality caused by certain factors
 - “Particularly vulnerable”
 - Leading to special treatments

Tools to identify the particularly vulnerable at end of life

- ❑ The risk chain model (Alwang et al.)
- ❑ Health determinants in moral investigation of health inequality

Tool 1: the risk chain model



Tool 2: Health determinants in moral investigation of health inequality

□ Three categories

- Individual choice (e.g., skydiving)
- Failing of social responsibility (e.g., health care)
- Nobody's fault (e.g., natural disaster)

Why is the risk occurring?

□ Risks

- End of life care not available
- End of life care offered but cannot be taken for various reasons (as opposed to voluntary refusal)
- End of life care offered but bad quality

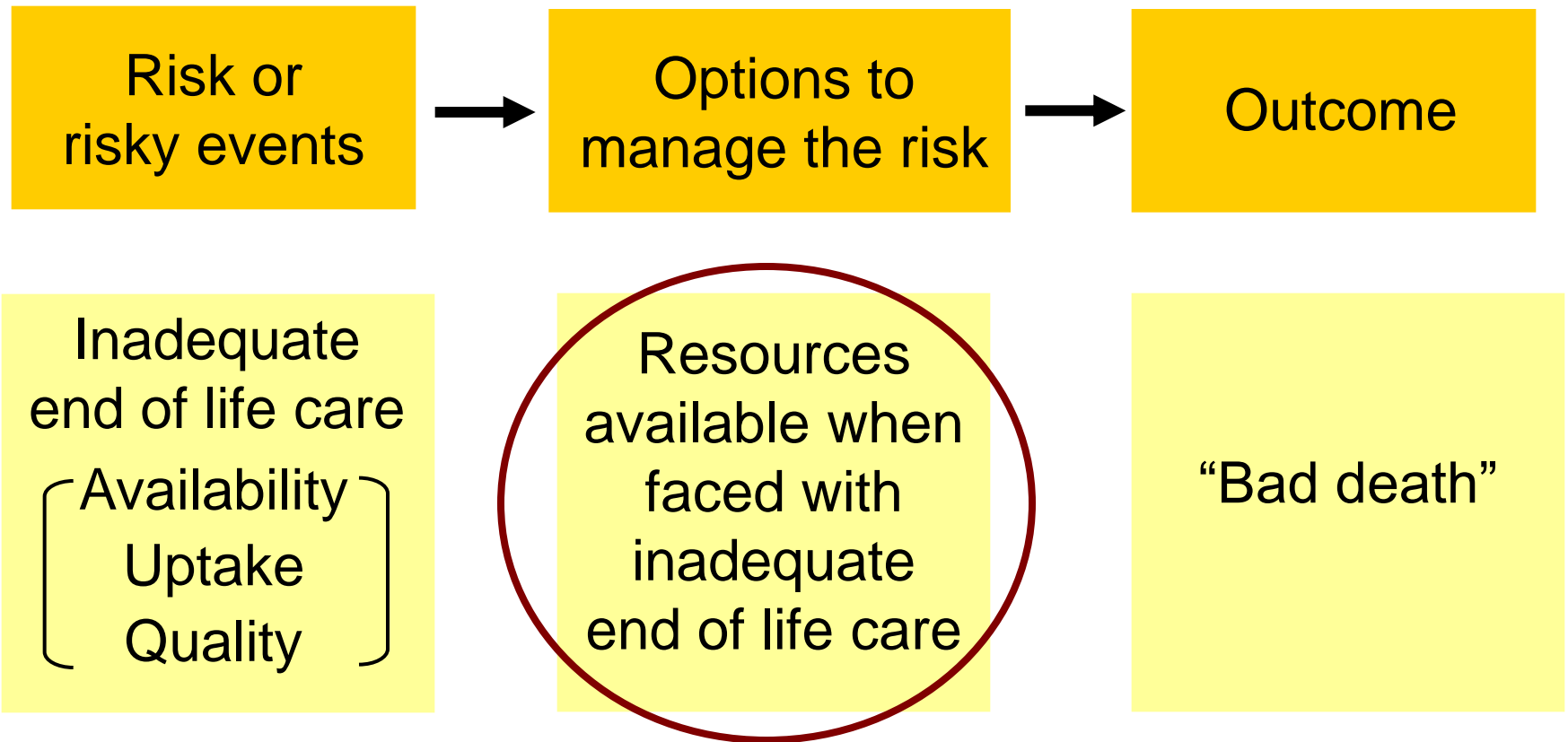
□ Reasons for the risk occurring

- ~~Individual choice~~
 - Failing of social responsibility
 - Nobody's fault
- } Beyond individual control

Inequities in end of life (the particularly vulnerable)

- When some people have increased risk for inadequate end of life care (in terms of availability, uptake, and quality) beyond individual control

The risk chain model



Inequities in end of life (the particularly vulnerable)

- ❑ When some people have increased risk for inadequate end of life care (in terms of availability, uptake, and quality) beyond individual control
- ❑ When people have less option to manage the risk of inadequate end of life care (e.g., can they complain? Do they have resources to claim what they deserve?)

Inequities in end of life (the particularly vulnerable)

	Those who have increased risk for inadequate end of life care beyond individual control	Those who have less option to manage the risk of inadequate end of life care
The elderly		
Children		
Women		
People with low SES		X
People in rural areas	X	
Cultural, religious, and ethnic minorities		X