



Caregiving: A biosocial approach to health and other human catastrophes

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Caregiving

- Caregiving_s: a. and n.,
- adj., characterized by attention to the needs of others, especially those unable to look after themselves adequately; professionally involved in the provision of health or social care;
- n., attention to the needs of a child, elderly person, invalid, etc.

_s As defined by the Oxford English Dictionary, 3rd Edition



Defining Caregiving Ethnographically

- Caregiving:
 - both the individual and collective human practice of giving care (protection, practical support, solidarity, etc.), including physical, emotional, interpersonal and moral assistance
 - Necessarily reciprocally linked to the process of care-receiving
 - the biosocial consequences of these care practices for caregivers and receivers.





Causes

Health Catastrophes

- Neurodegenerative disease
- Terminal cancer
- End-stage organ failure
- Epidemics with high mortality / morbidity

Natural Catastrophes

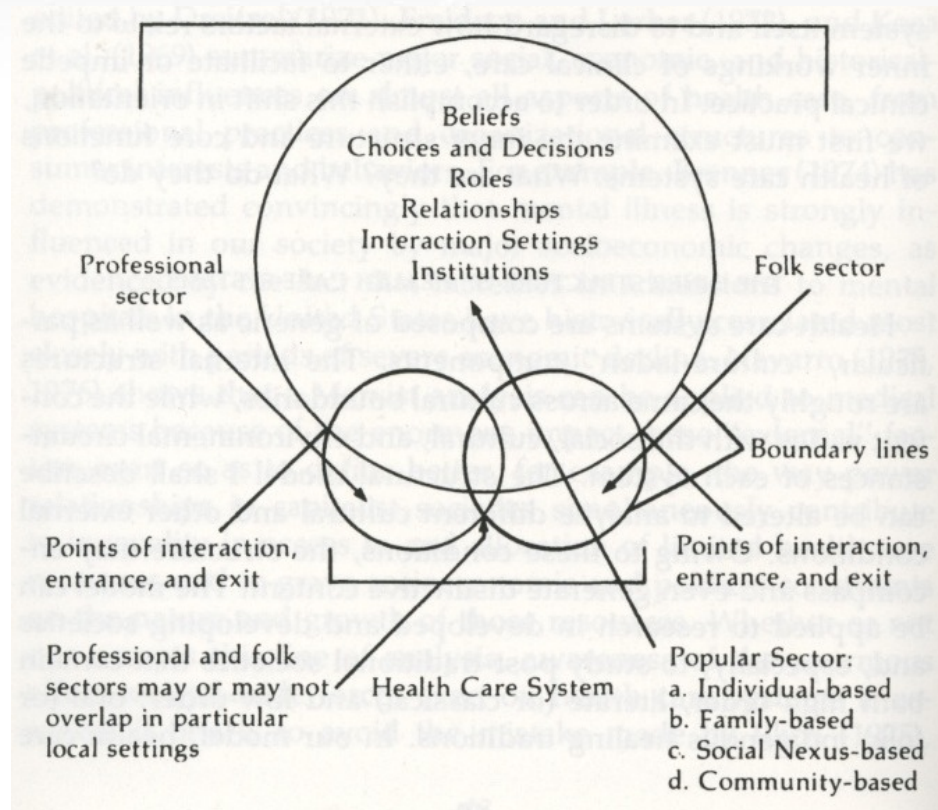
- Earthquakes
- Tsunamis
- Typhoons
- Floods
- Draughts

Manmade Catastrophes

- Political violence
- Economic crisis and depression
- Unintended consequences of “helping” interventions



Local World: Healthcare Structures and Practices §



§ figure 3. Kleinman, A. *Patients and Healers in the context of Culture*. pg. 50



Consequences



Cover Image. *World Mental Health Report*. Desjarlais et al. eds.

- Pain
- Trauma
- Loss of lives, limbs, functions
- Severe disability
- Threats to identity
- Loss of social and bodily integrity
- Interpersonal impact on the family and network
- Shifts in the moral order





Kathe Kollwitz. "Lamentation: in memory of Ernst Barlach (Grief).
1938. Cover Image of *Social Suffering*. Kleinman et al. eds.





Soldier suffering from shock. Photo from Shepherd, Ben. *The War of Nerves*. 2002





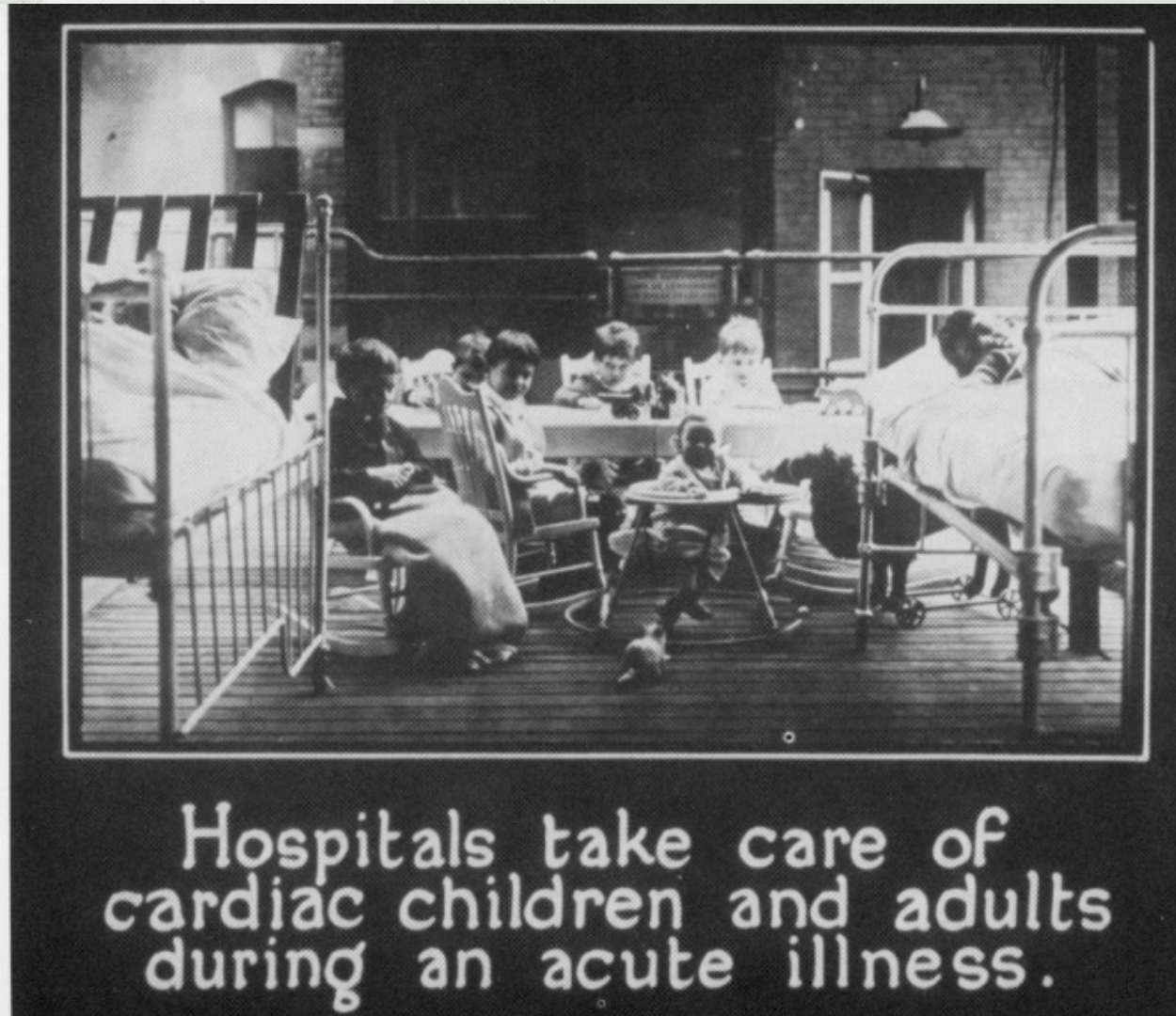
Zhensheng, Li. *Red-color news soldier : a Chinese photographer's odyssey through the cultural revolution*. 2003





Public health nurse providing home care in turn-of-the-century American tenements. Photo from Rosenberg, C. *The care of Strangers: the rise of the American hospital system*. 1987.





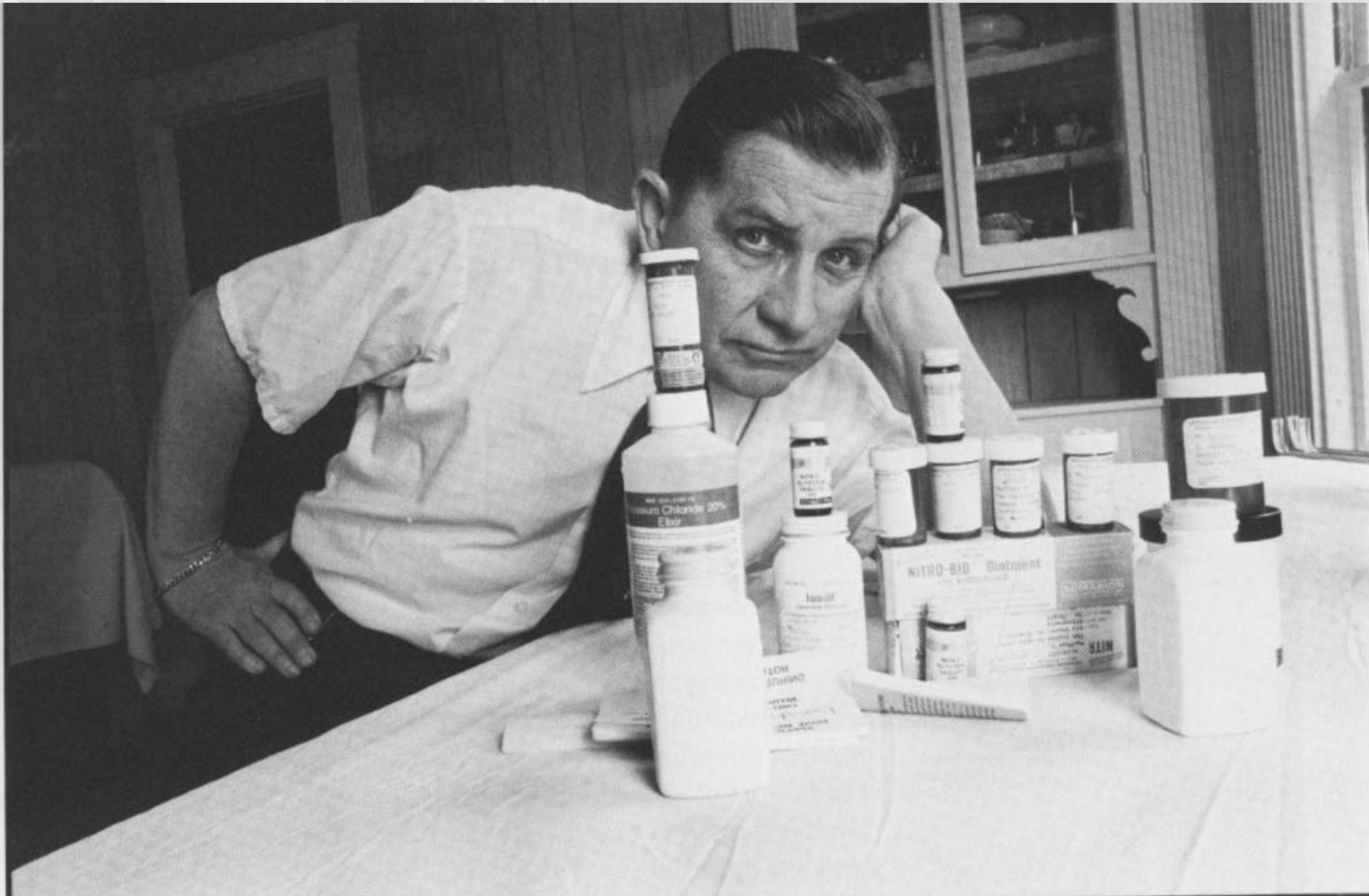
Promotional poster for hospital services in the USA. Photo from Rosenberg, C. *The care of Strangers: the rise of the American hospital system*. 1987.





An American woman with her friend as she prepares for a surgery. Photo from Rosenberg, M. *Patients, the experience of illness*. 1980.





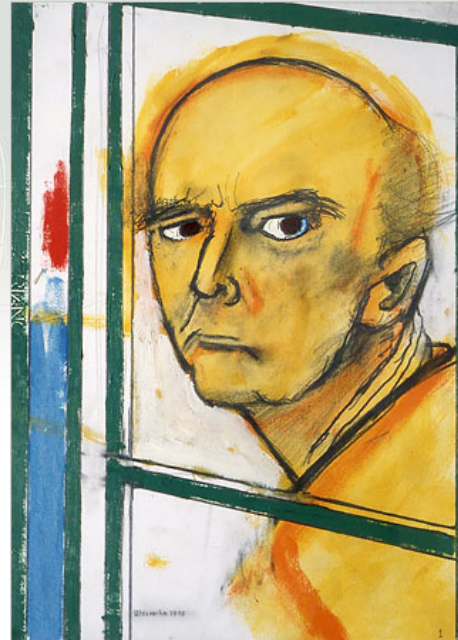
An American man with his myriad heart medications. Photo from Rosenberg, M. *Patients, the experience of illness*. 1980.





Cover image. *SARS in China*. Kleinman et al. eds





Self-portraits by William Utermohlen, an artist, who chronicled his experience of the progression of Alzheimer's through these portraits. Exhibited at the College of Physicians in Philadelphia. 2006





Caregiving

- I. Humanitarian Assistance
(caregiving at the collective level)
- II. Professional Caregiving
(individual caregivers and receivers)
- III. Self-care
- IV. Family and Network Caregiving
- V. Folk and Religious Caregiving



Philosophical Models

■ Heidegger

- “Care of the Self”
- Practiced as concern for the self



Emmanuel Levinas

- The “inter-human”
- Acknowledgement of the other precedes ontological values and epistemological inquiry

“the suffering for the useless suffering of the other, the just suffering in me for the unjustifiable suffering of the other, opens suffering to the ethical perspective of the inter-human” From: Levinas, E. (1998). *Useless Suffering. Entre nous: Thinking-of-the-Other*. New York, Columbia University Press. Page 65.





What is Caregiving?





Medical Anthropology

- Caregiving largely studied as a professional health service
 - Examples:
 - Practitioner patient relationship
 - Skilled nursing
 - Social work
 - Physical Therapy and Occupational Therapy
 - Rehabilitation
 - Hospice
 - Psychotherapy and pastoral counseling



Self-Help and Practical Guides

- “How-to” nursing care
- Long-term legal planning guides
- Advice on how to structure basic daily care: activities of daily living, for example
- Laws and structures for protection from harm and abuse





The Practice of Caregiving

- On a practical level, caregiving has little to do with medicine and the other helping professions.
- Partners, children, families, and wider social networks are responsible for the day-to-day realities of caregiving.



Caregiving and Status

- inverse correlation between status and caregiving.
 - Nursing and social work, lower status health professions provide the bulk of professional caregiving
- *Families*: lowest on the status hierarchy in the health system but possess the real expertise in caregiving
- *Women*: caregiving is often strongly associated with women's work cross-culturally



Nurse filling a syringe, July 17, 1976. Photo by Robert S. Halvey, Philadelphia Hospital Photographer.



What We Need

- A phenomenology of caregiving
- Research on family and network responses
- An interrogation of the affective and moral aspects of caregiving.
- Cross-cultural comparisons of caregiving dynamics
- Theory of caregiving as both an existential universal and an aspect of the local world
- Policy implications



A woman suffering from kidney disease pictured with her family. Photo from Rosenberg, M. *Patients, the experience of illness*. 1980.



Theoretical Framework

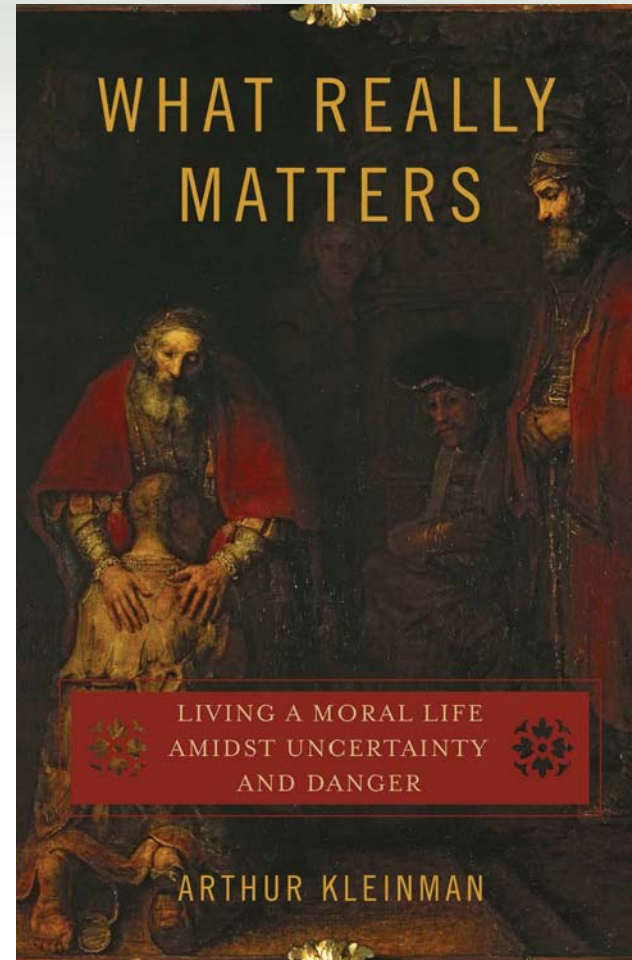


- My previous work on illness narratives and social suffering suggests an alternative theoretical framing for caregiving



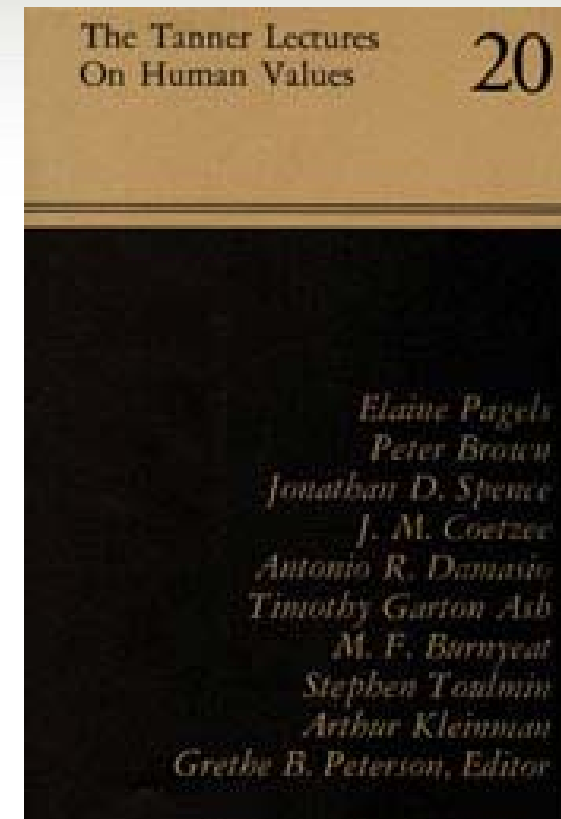


- Oxford University Press, 2006



Experience

- It is characterized by an orientation of overwhelming practicality in the face of real dangers and uncertainties.
- It is moral because there are certain things that are most at stake for collectives and individuals.
- Experience is realized in local moral worlds so that it is social as well as individual.



"Experience and Its Moral Modes: Culture, Human Conditions, and Disorder" - Arthur Kleinman (1999)



What is the “Moral”?

- *Moral Experience*

Life is about values. Just being alive, negotiating important relations with others, doing work that means something to us, and living in some particular local place indicate that moral experience is inescapable.

- *Moral Life*

Life is moral because we want to live a moral life. This includes moral imagination, moral responsibility, moral criticism, and moral engagement



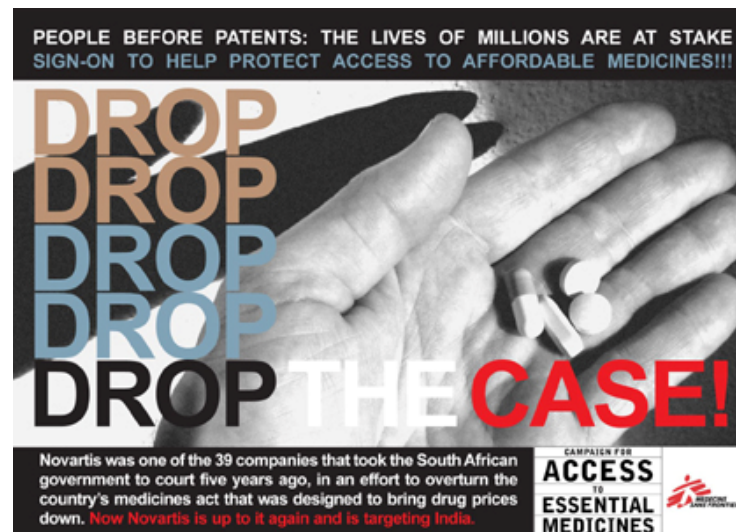
Morality and Caregiving

- Caregiving as an existential act that defines our humanity and our relationships with others. It is one of the things that really matters
- A basic response to the context of danger and uncertainty that defines the human condition
- In practice, not a 'burden' but a 'way of being'
- a basic aspect of moral experience and ethical aspiration
- In global culture of cynicism and sense of misplaced loyalty, caregiving is frequently perceived as one of the truly worthy objects of ethical commitment



Caregiving in Global and State Systems

- Caregiving is often enacted within systems of care regulated by state or international structures
- In this context caregiving can reinsert moral values into the world



- e.g. Médecins Sans Frontiers, International Human Rights Commissions, Health NGO's, etc.

MSF postcard campaign for affordable medicines.
www.accessmed-msf.org



The Anti-Heroic

- In contrast to heroic views of researchers and high-technology professional providers, an anti-heroic view seems more appropriate to caregiving
 - e.g. solidarity, criticism of oppressive structures, and small acts of resistance to the large social forces that dominate everyday life from bureaucracies to the global pharmaceutical industry (not dissimilar to Jim Scott's "weapons of the weak")



Sudanese woman and children during crisis in Darfur.
www.worldrevolution.org



Catastrophe and Caregiving: a dialectic



Cover image. *Dying for Growth*. Kim, et al.

- The study of caregiving is not only the province of medicine and other helping professions.
- Crucial role for humanities and social sciences as this dialectic is a fundamental aspect of social and daily life.



The Biosocial

- Caregiving is an ideal forum for exploring the concept of the biosocial.
- Biological processes and social processes are intimately interlinked in the quotidian process of caregiving.
 - e.g. time, basic self-care routines, partnership
- Families come to recognize the very real biosocial basis of relationship - the ways in which routine, life habits, intimacy are all deeply rooted in the body as well as the more abstract aspects of the self.
- Caregiving not only ties us as moral and ethical beings but as inhabited bodies that are vulnerable and deeply interconnected





Future Directions

- How does an emphasis on caregiving alter the object of inquiry for the Social Sciences?
- How do the intertwining biosocial, the moral, and affective processes in caregiving reframe social theory?

