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Rock, Paper, Scissors

Ideologies, Older People and End-of-Life Care

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Aims

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- Background & brief intro to study
- Present findings
- Contextualise within Bourdieu's theory of practice

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Background

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UK context: reports of "compassion deficit"

"Teach compassion"

"Recruit compassionate students"

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Compassion deconstructed

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Adapted from Chochinov 2007

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Background

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Doctoral study examining suffering in older people at the end of life

Setting: "Care of the elderly" ward in acute hospital in Northern UK

Ethnography: 186 hours observation

Informants: Patient (n=16), Staff (42), family & visitors (7) Patients: multiple morbidities, ambiguous prognosis, variable capacity, limited involvement in decision-making

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Findings

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Clinical practice informed by **ideologies** and bound by (unspoken) **rules**

The rules:

- are often shared by members of professions
- dictate decisions at key times
- help individuals navigate uncertainty

Bourdieu: habitus, doxa, capital and field

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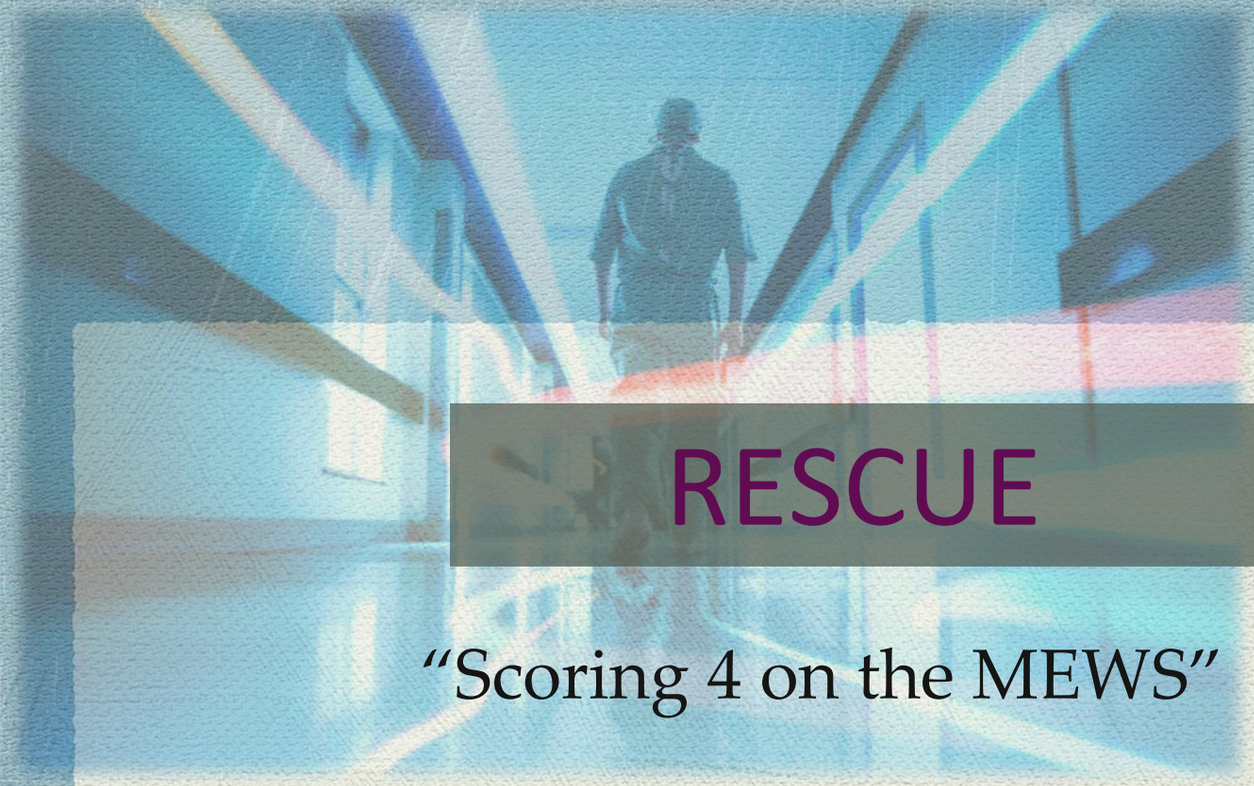
Acute care

Care of the Elderly

Palliative care



RESCUE

"Scoring 4 on the MEWS"

REHABILITATION

"I'll just go through my green crosses"

RELEASE

"The gift of a good death"

Not all ideologies are equal

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Care is generally good when team agree on approach

Problems arise when:

- Care transitions from one approach to another
- Patient, families or professionals disagree about correct approach

Society values heroism, battling against death, power of medical technology and bioscience

The “rescue ideology” dominates

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Two Case Studies

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1. *Ellen: "You've just given up on her"*

2. *Ned: "I'm bloody starving"*

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Ellen

Ellen (64) : Background: Stage IV heart failure, deteriorating renal function

Unconscious on arrival following seizure/stroke. Does not wake up fully

Family with her most of time; telling her to get better

Family concerned because: she has not eaten for 3 days and staff don't seem to be concerned

Nurses (outside room) discuss probably dying: thishas not been discussed with family – "the consultant needs to make the decision"

Over weekend, family distressed - on-call dietician places nasogastric tube, feed is commenced

"You've just given up on her"

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Ellen

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Increasing oedema
Vomiting and aspiration
Metoclopramide syringe driver commenced
Sited in arm – oedema – ineffective – resited centrally
Pressure sore to nostril
Nurses distressed ++

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Ellen

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Discussions about dying curtailed twice due to family distress and anger, & professional anxiety about talking about dying

Medics retract due to clinical ambiguity

5 days later doctor tells family Ellen is dying. Feed discontinued, tube removed, other family called to bedside. Dies three hours later.

Nurses angry ++

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Ellen: lessons learnt

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Dying on admission. Palliative approach indicated

uncertainty of diagnosis → **uncertainty of prognosis**

Uncertainty → rigid adherence to rules

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Ned

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94 years old

Dementia for past 4 years

Widowed

Admitted with chest infection - ?aspiration pneumonia

Weight loss, response to antibiotics uncertain

Deemed no capacity

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Ned

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Consultant: “I think of it as a battlefield, when we have someone in front of me who is moribund we do everything. But my other hat is as a human being...he's 94, lives alone, wife died...is it treating with all the tubes and things that are giving more trouble? The only reason I support the feeding is that he wasn't bedbound, he was mobile. If he had been bedbound, incontinent, needing all cares, I would have been different.”

Daughter: “It's difficult, isn't it? How long would it be for? Forever? He loves shepherd’s pie”

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Ned

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"I will be guided by you. We can take a risk and feed him by mouth"

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Ned

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Ned's daughter goes back into his room and takes the NBM sign from the door. "guess what dad, they've said you're allowed some lunch" "oh good" - a mug of soup is brought and she begins to feed him. He slurps a spoonful, coughs, smiles and sighs. "I were bloody starving."

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Three Ideologies

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	ELLEN	NED
RESCUE	NG tube	Further course of antibiotics, NG tube, ?PEG/RIG tube
REHABILITATION	NG tube	Speech &language therapy, NG tube (temporary?)
RELEASE	Mouth care, family support, comfort measures and symptom control	Risk assessment, oral food and fluids as tolerated

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Bourdieu: Professional habitus

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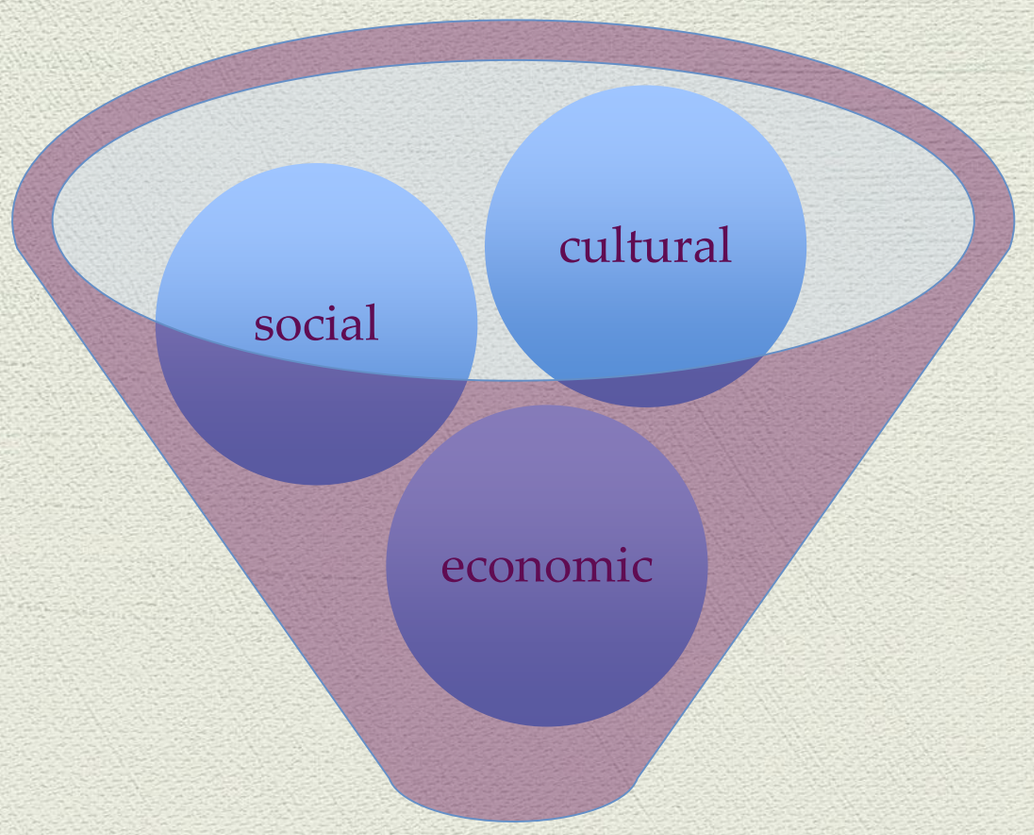

Symbolic capital

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Three Ideologies

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Negotiating ethical issues at life's end is influenced by power dynamics between professions and disciplines

Clashes between ideologies of care introduce significant ethical problems when clinical decisions need to be made in an atmosphere of ambiguity

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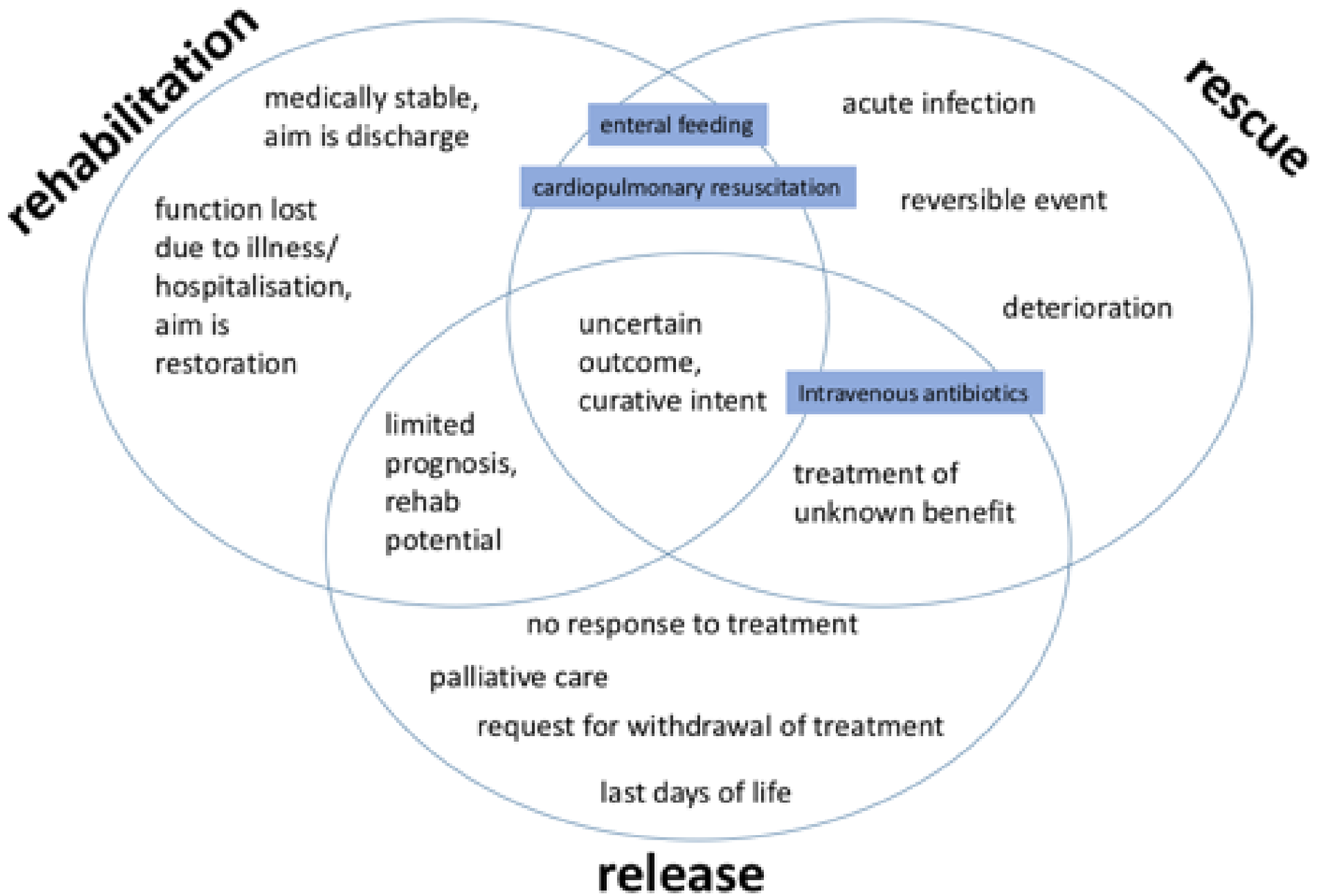
Three Ideologies



Conclusions

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- Uncertainty is difficult; leads to increased adherence to “the rules”
- The "**ideology of rescue**" dominates: default position in acute hospital ward
- **Iatrogenic suffering** can result from well-intentioned interventions

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Recommendations

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Observational methods offer insight into situated nature of ethically challenging situations

Professional differences in capital lead to different degrees of agency in decision-making; policies focusing on enabling development of shared habitus may succeed where overly prescriptive ones have not

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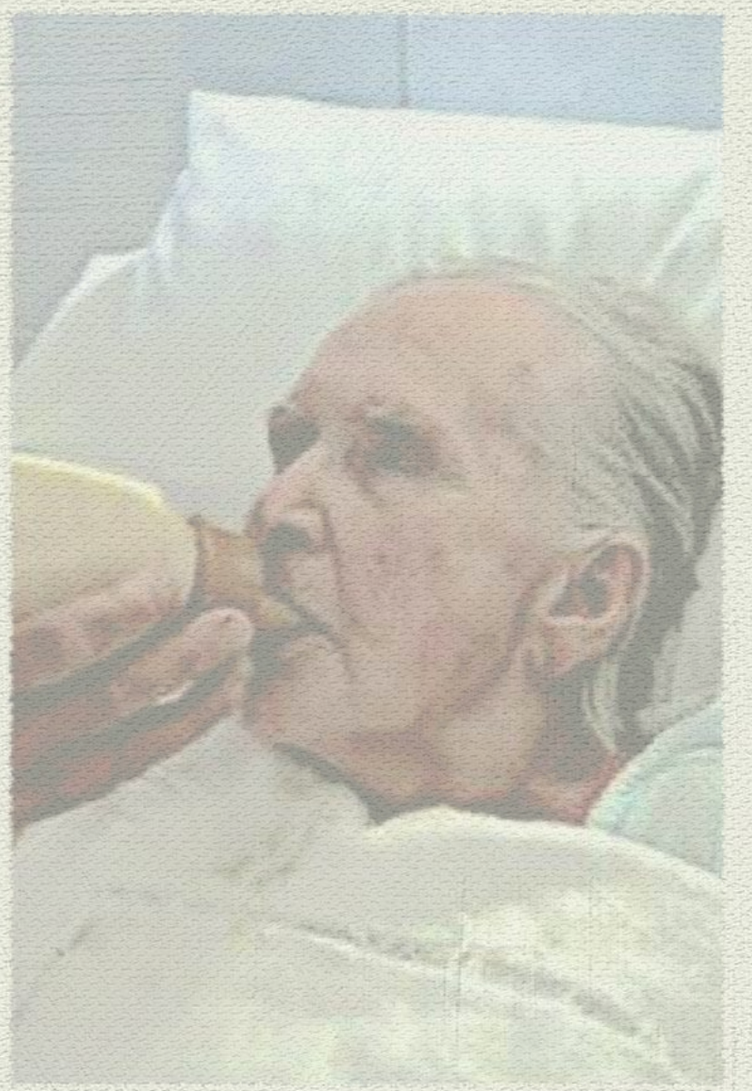
"We are the guardians of what we witnessed" [Behar 2014]



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Further reading

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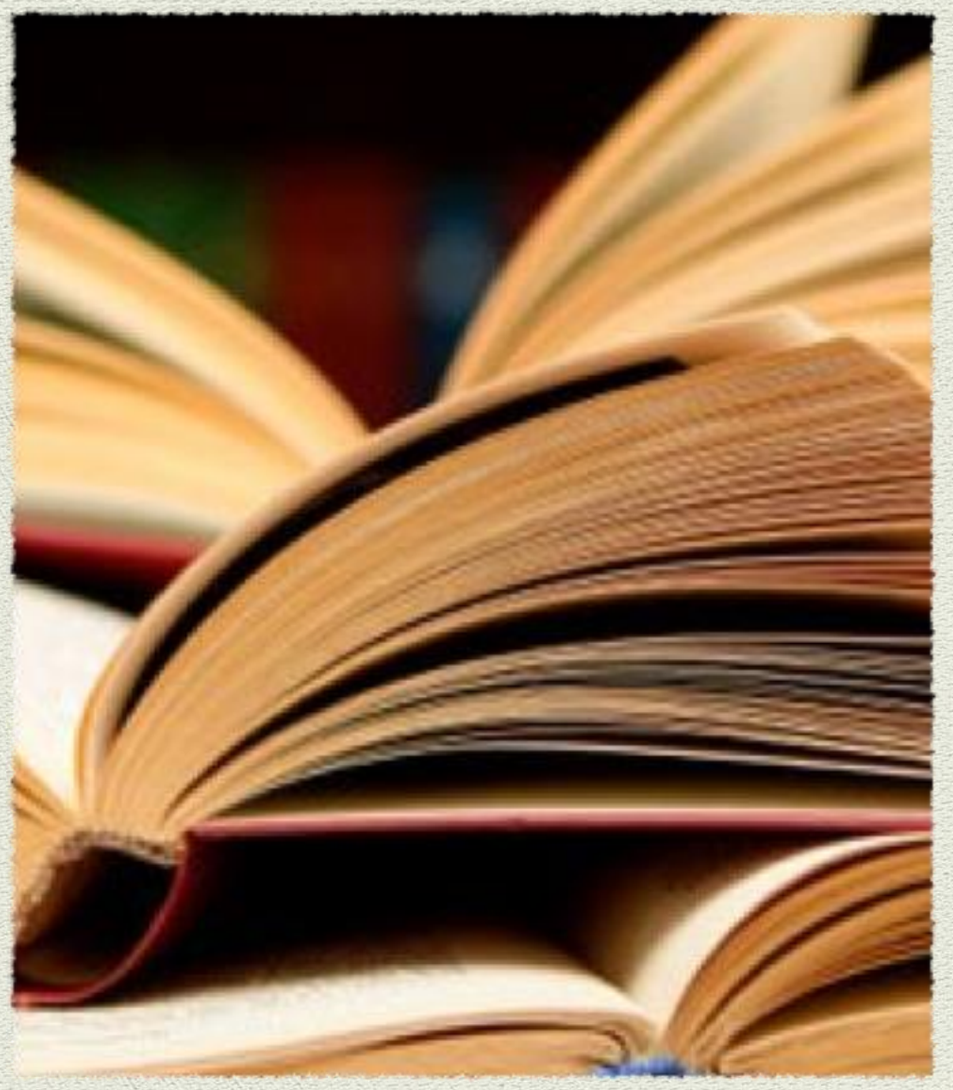

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