Late Stage Dementia: Providing, Comfort, Compassion and Care-New Dimensions

Hospice of Waterloo Conference
November 17, 2016

Michael Gordon, MD, MSc, FRCPC
Medical Program Director: Palliative Care
Baycrest Geriatric Health Care System
Professor of Medicine, University of Toronto

Goals and Objectives

- Goals- to address clinical, ethical and educational challenges that face health care providers and families for those living with late-stage dementia
- Objectives- to provide health care providers, families health care professional trainees with processes by which to address clinical and ethical dilemmas that occur in late-stage dementia
- To explore some contemporary new dimensions in this area of care

Defining the Problem (1)

- Industrialized nations like Canada face a rapidly aging population
- Even with new advances, diseases for which treatments have been developed ultimately have a terminal phase
- Malignant conditions are understood by the health care professions and the lay public as having a *terminal phase*

Defining the Problem (2)

- A terminal phase is not always considered with conditions that cause dementia-but must be to properly plan care
- Much of the focus on dementia is related to diagnosis and treatment(s)
- Current pharmacological treatments are at best symptomatic or have a modest delaying effect on disease progression
- Cultural variation in our populations are affecting how care is provided in ways previously unanticipated

Defining the Problem (3)

- The focus of medical treatments for dementia:
- Improving cognition and awareness
- Decreasing the rate of progression
- Controlling behavioral problems
- Treating associated conditions – nutritional deficiencies, swallowing disorders, ability of function (ADLs)

Defining the Problem (4)

- Non- medical treatments focus on:
- Support and education for caregivers
- Improving the milieu of life
- Providing as much quality as possible to individuals with these progressive disease(s)
- Finding ancillary modalities of support: ADLs and living arrangements
- Preparing patients and families for “the end”

Changes in Perception (1)

- For years “senility” was term used for elders with dementia
- Not considered within the framework of a defined medical condition
- Gradual recognition of “disease” entity and various pathologies: Degenerative (Alzheimer’s, Pick’s, Fronto-Temporal, Lewy Body etc. and vascular and mixed causes)

Changes in Perception (2)

- Now recognized as one of the great challenges of modern society
- Many recent articles on societal costs and impact on families
- Greater emphasis on detection and diagnosis
  - Question about merits of earlier and earlier diagnosis
  - Commercialization of detection methodologies

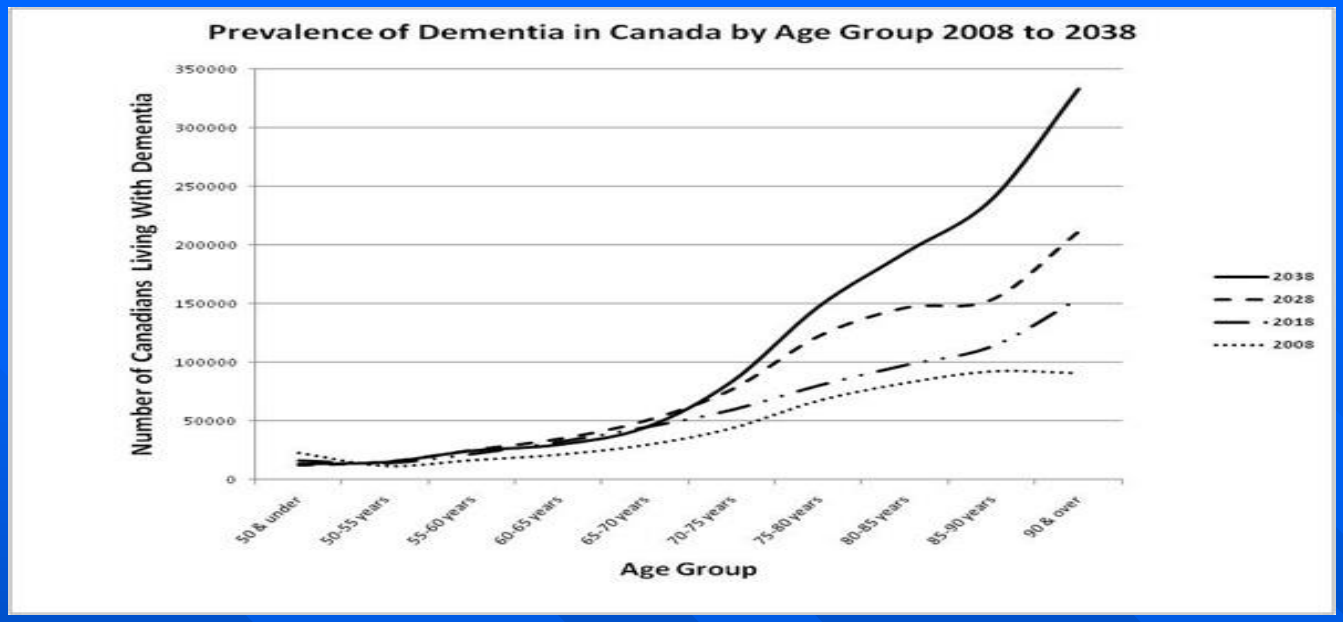
Changes in Perception (3)

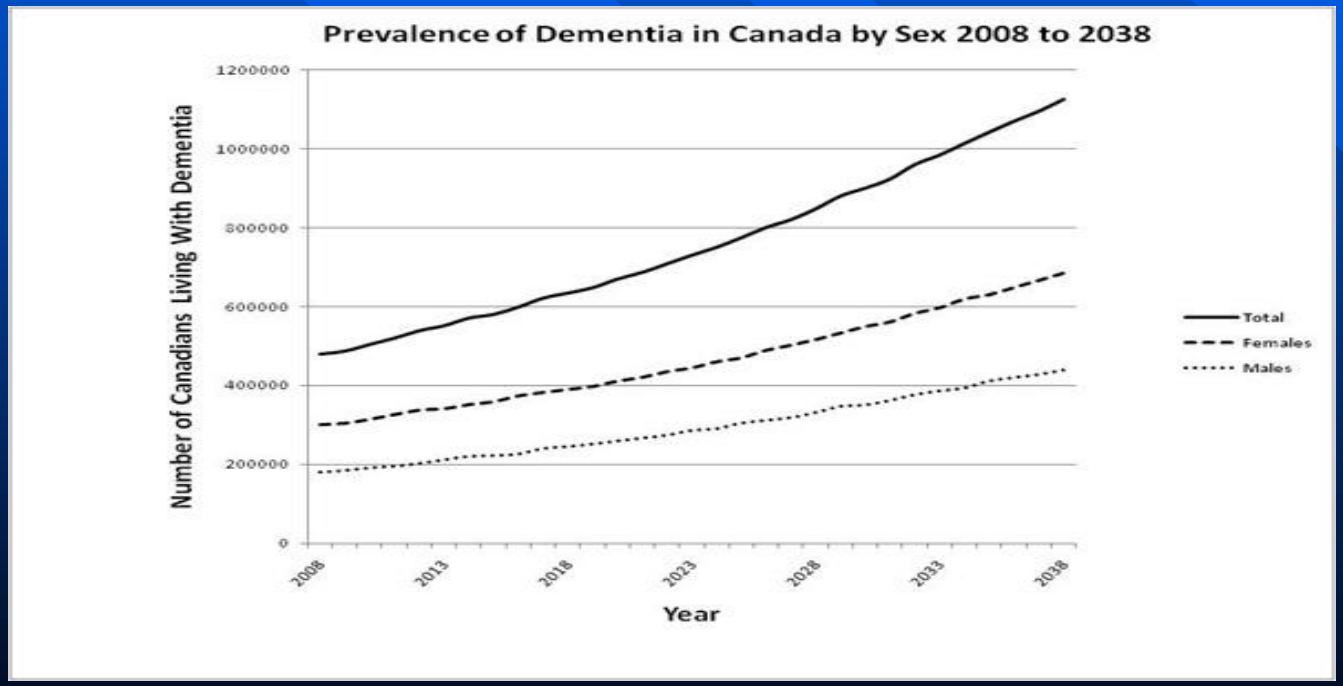
- Concern about the “perfect storm”= increased age of population, increased prevalence of dementia, legalization of Physician Assisted Dying or Suicide (PAD or PAS)

Alzheimer Society

Rising Tide

The Impact of Dementia on Canadian Society


Prevalence of Dementia in Canada by Age Group 2008 to 2038
Number of Canadians Living With Dementia
350000
300000
250000
200000
150000
100000
50000
0
50 & under
50-55 years
55-60 years
60-65 years
65-70 years
70-75 years
75-80 years
80-85 years
85-90 years
90 & over
Age Group
2038
2028
2018
2008


Prevalence of Dementia in Canada by Sex 2008 to 2038
Number of Canadians Living With Dementia
1200000
1000000
800000
600000
400000
200000
0
2008
2013
2018
2023
2028
2033
2038
Year
Total
Females
Males

But!!! (1)

- Recent studies suggesting that in last 10 years an actual decline in incidence of dementia in UK and Denmark (reported in Lancet) and communicated in NY Times July 16, 2013
- If so why?
- If so what might it mean for predictions?

But!!! (2)

- A 2 year multi-domain intervention of diet, exercise, cognitive training, and vascular risk monitoring versus control to prevent cognitive decline in at-risk elderly people (FINGER-Finland): a randomized controlled trial-Lancet March 2015
- Overall cognitive performance favored the intervention: a 25% greater improvement in the cognition score in the intervention group
- *Message—keep doing cross-words while you run and eat greens*!

Case 1

- 82 year old female
- In patient ComContCare ~ 1year
- Mixed Multi-Infarct/Alzhemier's
- PEG inserted prior to transfer to Baycrest
- Patient stable
- Family now wants to remove tube

Case 1 (2)

- Family believe “she never would have wanted to be like this” and “we put in the tube because we hoped she would improve”
- Although staff understand position of family - have great difficulty in carrying out request

Case 1 (3)

- Physicians will not write order for “personal” moral/religious reasons
- Another MD writes order
- A great deal of turmoil among staff
- What are the options?
  - Refuse to stop the feeding tube?
  - Educate the staff quickly
  - Have the family speak to the staff about their reasons?

Case 1 (4)

- Because of turmoil among staff patient transferred to palliative care unit
- Dies within 10 days, in coma, family grateful for assistance
- During debriefing the staff of original floor bemoaned the fact that they had not heard the reasons directly from the family

Case 2 (1)

- 93 year old female admitted to Baycrest directly from a hospital in Florida
- Previous stroke with good recovery
- Some progressive cognitive decline—but able to enjoy many aspects of life
- Looked after by PSW full time
- In Florida for winter—own condominium

Case 2 (2)

- While breakfasting, PSW turns from table for a few moments
- Patient found to be blue and unresponsive
- EMS called: Respiratory/cardiac arrest
- CPR—food expelled—many minutes

Case 2 (3)

- Survived but in Florida hospital, no recovery of consciousness
- PEG inserted
- Direct transfer to Baycrest
- Minimally conscious state
- Otherwise stable

Case 2 (4)

- Few days after admission, family presents “living will” which they claim they did not know about (said it was never discussed)
- States quite clearly that she would not want “artificial feeding”

Case 2 (5)

- Family meeting with senior staff and ethicist—informed son and daughter that it would be our duty to respect mother's clearly stated wishes and either remove or cease to use PEG

  (per Health Care Consent Act)
- Family refused—said "she could not have understood what she was signing"

Case 2 (6)

- Case became contentious:=Consent and Capacity hearing—agree with Baycrest
- Appeal to Superior Court of Ontario=agreed with family
- Decision made by Baycrest to not appeal further—clearly very meaningful for children that they “not let her die—they could not live with themselves if they did” = still in minimally conscious state - 1.5 years later

Case 3 (1)

- 89 year old male European immigrant Holocaust survivor
- Moved into retirement facility attached to a long-term care facility after death of his wife
- Managed well for 3 years
- Gradual and progressive cognitive decline- resulting in moves to parts of facility providing increased support

Case 3 (2)

- Increasing behavioral problems with wandering, emotional outbursts, disruptive behavior
- Modest improvement with medication changes
- First episode of aspiration pneumonia – treated in associated CCC hospital with antibiotics-associated severe delirium
- Following series of infections (?pneumonia, UTI)
- Non-specific but evidence of increasing discomfort

Case 3 (3)

- Physician outlines possible diagnoses and possible further tests some of which would require transfer to a general hospital-- questions UTI
- Family wants to understand prognosis and about treatments for agitation and apparent discomfort
- Physician expresses reluctance to give potent/opiate analgesics as she does not “want to hasten death”

Case 3 (4)

- Gradual decline in function, no oral intake and family refused feeding tube:

1. Should the physician search for treatable causes of decline?
2. Is there a good reason to withhold opiates?
3. Will giving opiates hasten death?
4. Can the physician be charged with committing euthanasia by giving opiates in non-malignant disease?

Case 3 (5)

- Death after another week of decline with evidence of significant discomfort
- After death the family expressed dismay about the reluctance of physician to provide more robust palliative care interventions including adequate doses of

Challenges in Ageing (1)

- The success in ageing has led to viewing these aged individuals (successful in their efforts) as a “burden” to society
- This is especially the case for frail elders suffering from dementia

Challenges in Ageing (2)

Implications of The care of the Elderly:

- Clinical-what interventions are suitable: multiple, chronic medical problems
- Economic-what is society prepared to spend on the care of the elderly- and who will pay for what?
- Ethical- what is the impact on society's fabric from the decisions that are made?
- Educational – how well are we preparing our trainees for the aging future?

What Should be Our Goal?

- Continue to provide the means to decrease illness and disability
- Increase life expectancy at all ages but especially *active* life-expectancy
- Improve society's value of the aged irrespective of level of function: an integral part of our community
- Provide Care in a humane manner

Dementia (1)

- The care for dementia-afflicted (is this a *good* term?) individuals is the symbol of our society's view of its members
- If we "abandon" affected patients and "off-load" increasing levels of responsibility to families we will undermine our societal and care-giving mandate and give a clear message as to our societal values

Dementia (2)

- If we do not accept, recognize and communicate as health care professionals that most of the causes of dementia have a "terminal phase" we will fail to provide proper palliative care to those in great need. They and their families will suffer unnecessarily

Ethics Implications (1)

Aging-related issues- major challenge in contemporary bio-ethics:

- Truth telling about dementia diagnosis,
- End-of-life: e.g. Feeding issues, CPR
- Risk-taking by patient, family and staff
- Degree of care provided, use of novel medications, ``salvage therapy``
- Implications of rites and rituals at the end of life

Ethics Implications (2)

- Role of institutions vis a vis family
- Ability of families to absorb role and costs
- Advance care planning: understanding of trajectory of the disease
- Resource allocation- costs of all aspects of care and priority-setting
- Genetic profiling
- Pre - clinical diagnosis and “markers”

Revealing the Diagnosis

- Should the diagnosis be revealed to the patient?
- Families often request withholding truth
  2015 USA report, "found that only 45 percent of people with Alzheimer's disease or their caregivers say they were told the diagnosis by their doctor"
- Balance of principles of non-maleficence and autonomy
- Most recommend truth-telling: challenge is the process/family involvement - can't plan without knowing

Advance Care Planning

- What if any is the place of a “living will”?
- Is the document important and if so to whom does it speak?
- Is it possible to anticipate the future sufficiently to fill out the “grid” AD?
- Most important process is discussion and definition of important values of patient that family and others must consider when decisions made
- Choosing the right SDM(s) critical as well

Weight Loss and Alzheimer's Disease (1)

- Weight loss/cachexia frequently in AD patients, especially in the later stages (White-JAGS,96)
- Nutrition often the major focus of family and health care providers
- Weight loss $\geq$ 5% in any year before death-predictor of mortality (White- JAGS, 98)
- Weight loss in AD not limited to severe dementia (Cronin-Stubbs BMJ;1997)

Weight Loss and Alzheimer's Disease (2)

- Cause is multi-factorial:

  Socio-environmental, psychological, medication use, atrophy of mesial temporal cortex, "other".
- Aversive feeding behaviours: Related to global deficits, confusion, inattention, loss of neuromuscular co-ordination

Weight Loss and Alzheimer's Disease (3)

Serious consequences of wt. loss:

- Decreased immunity- increased infections
- Loss of muscle mass = muscle atrophy, functional decline, falls and fractures
- Skin atrophy = risk of ulcers
- Increased risk if institutionalization

Weight Loss and Alzheimer's Disease (4)

- Some beneficial intervention programs but a time may arrive when no longer able to take oral nutrition
- Then---we must rethink the role of tube feeding in patients with advanced dementia (Gillick MA, NEJM, 2000)

Beneficence

- Purported benefits: Survival, Aspiration, Malnutrition, Comfort
- “We can’t let him just starve to death”
- To what degree do the cognitively impaired at the end-of-life sense hunger and thirst?
- Extrapolate data from terminally ill cancer patients
- Majority: no improvement in function or QOL

Non-Maleficence

- Use of restraints
- Use of psychotropic medication
- Aspiration

Autonomy

- Having a sense of control over decision-making is a key component defining high quality end-of-life care*
- Active participants, informed, respect wishes
- Substitute decision-making

**Singer PA, JAMA 1999*

Autonomy: decision-making

- Decision-making is flawed
  - lack of advance directives or discussions
  - "Having the Conversation"
  - poor understanding of substitute-decision making: also issue of trust of SDM
  - poor transfer of knowledge between health care team and SDM

Justice

- With limited medical resources and questionable benefits, is tube-feeding in advanced dementia justified?
- Differential international practice:
  - allocation of resources (e.g.pub. funded)
  - access to technology
  - attitudes towards death and dying
  - cultural influences

CPR in the Elderly and those in Long- Term Care

- In the community dwelling elderly CPR may have a benefit for those who receive CPR quickly and have a reversible cause(e.g. MI, arrhythmia)
- In Long-term care cause is usually multi-factorial: rather than a cardiac arrest “death” has occurred

Why Is this an Issue?

- Long-history of CPR in health care
- Deemed to be a “life-saving” therapy
- Media depiction of CPR

  dramatic and beneficial
- Fear of “abandonment” in later life
- Real outcomes in frail elderly
- Very poor depending on nature of study and criteria for “success”

Clinical (1)

- "True" Long-term care population characteristics:

  *Permanently a*dmitted*

  Very frail, and dependent

  **Co-morbidities: often with dementia*

  Multiple medications

Clinical (2)

- Impact of Nature of Long-term care facilities:

  D*elays from BCLS to ACLS*

  R*arely know time from arrest to observation*

  U*sually do not know initial rhythm*

Ethical (1)

- Much of the controversy over CPR/DNR policies are really ethically based:
- Autonomy of decision-making- is there really a place?
- Beneficence: who decides what is “good”?
- Toronto Case March 2015: Family sues physician, hospital over DNR order-relatives alleges physician and Hospital did not act on 94-year-old`s wish to be kept alive

Ethical (2)

- Do we have to tell patients and their families of decisions being made?
- What input does the staff have when they don’t agree with a decision?
- Is resource allocation an ethical issue in this arena?

Ethical (3)

- Is there a role for religious respect in decision-making?
- Is it so that Physicians are not obligated to provide a treatment that they feel will provide no benefit?
- Recent Ontario case which went to the Supreme court suggests ``not necessarily so``

Ethical (4)

- If an “arrest” occurs without a DNR order, it should logically and from evidence result in CPR *only* if it is a true cardiac arrest = witnessed and unexpected- *otherwise it is a death*
- *New defibrillators make it harder to avoid CPR*
- Must explain to families that CPR has a very limited role at the end of life in frail elders and is associated with traumas and indignities *and*

Ethical (5)

- CPR does not mean cardio-pulmonary *resurrection*

Ethical (6)

- What about the role of euthanasia and/or Physician Assisted Suicide in Canada?
- Very controversial: Exists in a number of European countries with Netherlands the ``pioneer``
- Gradual acceptance in some U.S. States (Oregon, Washington, Montana and Vermont)
- Recent over-turning of prohibition of PAS in Canada (2015)
- Must wait for legislation to see the impact

Summary

- During the later stages of diseases that cause dementia it is important to decide upon palliative care approaches which includes the proper treatment for all symptoms including restlessness, pain and other discomforts
- The use of appropriate medications including opiates should not be shunned by physicians using the “fear of hastening death” as the rationale

Conclusion (1)

- Ageing is the 21st century success story
- Goal: increase quality of life not just life expectancy
- Individuals with dementia who require long-term care present a special challenge
- This is especially the case as the enter the terminal phase of their condition

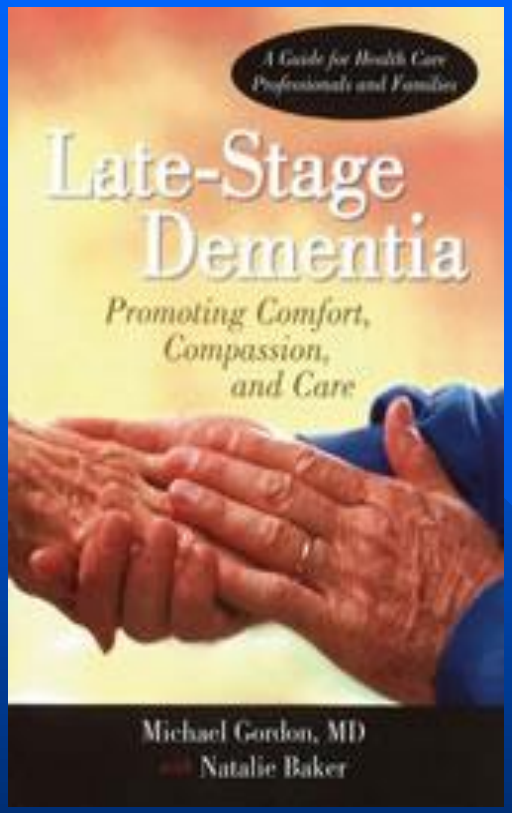
Conclusion (2)

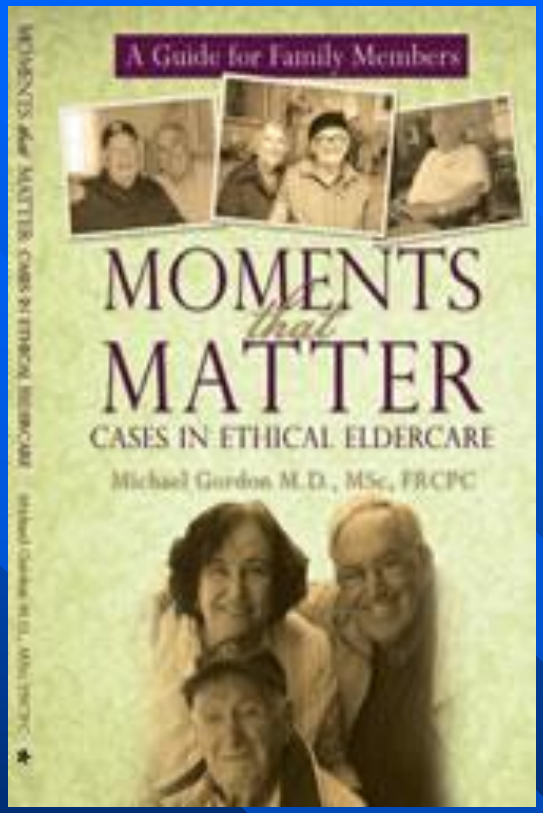
- Challenge is to meet the needs of this frail and vulnerable population and their families in an acceptable, dignified and humane manner

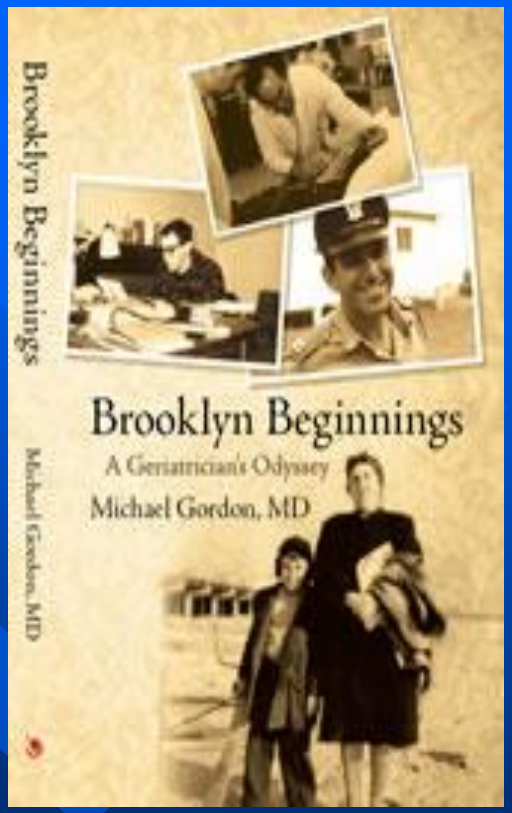
Conclusion (4)

"the life span of any civilization can be measured by the respect and care that is given to its elderly citizens and those societies which treat the elderly with contempt have the seeds of their own destruction within them".

Attributed to Arnold Toynbee







http://www.drmichaelgordon.com/

http://www.parentingyourparents.ca/