

INFORMAL CAREGIVERS FROM INVISIBILITY TO VISIBILITY

CULTURE(S) OF CAREGIVING

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INTRODUCTION

What is caregiving?

Broad approach

Culture(s) of caregiving

HISTORICAL GLIMPSES

- Neanderthal man?
- Greeks: exposure on hillside
- Romans: dumping unwanted babies
- 16th century: Peter Laslett and Tudor parishes
- 20th century: Rise of carers movement
- Mary Webster: feisty feminist and carer

STORIES

SCOTTISH: Back from WW1, shellshocked and gassed. What a life!

DUTCH MIGRANT/NEW ZEALAND: Huberta Hellendoorn “Madonna in the Suitcase” book about bringing up her daughter with Downs’ Syndrome

CULTURE/S OF CAREGIVING

These include:

- FAMILIES
- COMMUNITIES
- ETHNICITIES

FAMILIES

- WHO?
- MOTHERS/FATHERS
- SIBLINGS
- GRANDPARENTS
- CHILDREN
- WHAT IS THE EFFECT? BURDEN?
TRANSFORMATIVE EXPERIENCE? OR
'AMBIVALENCE'

COMMUNITIES

- SOCIAL CAPITAL (Putnam, 2001 : bonding/bridging networks

Bonding -

- Families: friends: neighbourhoods
- Support Groups

Bridging networks:

- Professionals – building networks with professionals: bridging the gap. But professionals come and go – and often make a ‘railway station’ of the home.

ETHNICITIES - issues

- Language: do we share the same linguistic interpretations and words for caregiving?

Caregiving could depend on

- Cultural perceptions of 'disability'
- We need to understand the cultural premises on which others operate

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ETHNICITIES issues

Mental illness-example 1

Mental/intellectual disabilities –

- Loss of ‘face’
- ‘I feel that I am inferior to others and I feel sad to have a family member with mental illness. I dare not tell others that there is a person with intellectual disability in my family’

Q: So does mental illness isolate both the sufferer and the caregiver?

Examples 2

Songye (Bantu) society

Physical issues

- Three categories of physical problems or 'deviation' in children: ceremonial: bad: faulty.
 - Ceremonial: twins; children born with cord round neck, hands or feet first. A ceremony is held to give special names to these children, who may then be used as spiritual leaders.
 - 'Bad' children are associated with the dead: are 'albino', 'dwarf', hydrocephalic children. They are expected to die, so only basic care is given.
- 'Faulty' children are those with bodily deformities (Ingstad and Whyte, 1995). Care is given.

DEMENTIA – EXAMPLE 3

- A normal part of ageing, (Arabic peoples) but with a mental health aspect, and therefore stigmatised.
- Croatian community members equally believe there is a mental health issue, and therefore stigmatised.
- (Alzheimer's Australia study, 2008)
- Dementia is considered in some countries to be 'loss of self', or 'as the result of witchcraft' or 'punishment for previous sins
- And therefore caregivers do not always seek help.

CAREGIVING? Questions

- With 'disability' as a cultural construction, with aspects of shame, of 'bad' and 'faulty' and stigma, how do we perceive caregiving? What are the effects of such a cultural construction?
- Can we in fact use such a term universally?

Ingstad and Whyte do use it: in terms of 'basic care' and interpreting how these children are perceived and treated by the local community.

When/if cultural constructs and beliefs persist into a migrant situation – what happens?

MIGRANT

- Homeland versus hostland
- Affiliate caregivers, who feel the stigma and refuse to seek help
- Lack of wider support systems? Or lack of acceptance of these?
- Intergenerational issues

VALUE?

- Why do we need cultural information?
- Learn from other cultures?
- Checking language barrier
- Improved services in NZ
- Sensitivity to others in our own culture