The Chinese University of Hong Kong
The Nethersole School of Nursing
CADENZA Training Programme

CTP004 – Dementia: Preventive and Supportive Care

Web-based Course for
Professional Social and Health Care Workers

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Chapter 7:
Mapping effective care model for dementia: from assessment to evaluation

Course Outline

- Innovative dementia care programs/practices in primary care community home support service: International experiences
  - Cooperative Dementia Care Clinics in US
  - A partnership between a managed care health system and an Alzheimer's Association in US
  - A specialist home support service for older people with dementia in UK

- Feasibility of adopting the new care practises in Hong Kong context

What are the problems in dementia care programs / practices?

- Heavily relies on medical specialists for management of older adults with dementia, which leads to a long waiting list to the services and delay of diagnosis making and provision of treatments
- Needs of patients and families are not fully addressed by service providers in the community level (caregivers still experience a high level of burden)
- Insufficiency in collaboration among health care and social service sectors
- Fragmented dementia care services…

Why do we need innovative dementia care programs / practices?

- Progressive and debilitating nature of disease that demands ongoing and specific supportive services for family caregivers during the course of illness
- Strives for proactive and effective care models for the management of dementia to facilitate patients to continue living in the community (as a substantial portion of older adults with dementia lives in the community)…

Three innovative dementia care programs/practices from Western countries will be introduced in the following sections.

Cooperative Dementia Care Clinic in US

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Cooperative Dementia Care Clinics

Background of the clinics

- High medical costs for patients with dementia as compared with non-demented older adults in
  - direct costs in emergency room and inpatient treatment
  - management of behavioral and psychological symptoms
  - medical comorbidity
- Care of patients with dementia that requires specialty service covers ranging from initial consultation to on-going follow-up

(Lessig et al., 2006)

Cooperative Dementia Care Clinics

Background of the clinics

- Designed a dementia specialty care, including
  1. Diagnosis
  2. management of psychological and behavioural symptoms,
  3. medical comorbidity, and
  4. caregiving issues and psychosocial intervention
- Memory Disorder Clinic at the University of Washington facing a long waiting list and a great demand of follow-up consultation without increase the resources
- Developed a non-conventional clinic with shared medical appointment with patients and caregivers

(Lessig et al., 2006)

Cooperative Dementia Care Clinics

Critical features of CDCC

- Considered patient and caregiver as a unit
- Focused on the existing problems and prevention of any potential complications
- Emphasized on patient-physician partnership
- Attention was paid to biomedical and psychological aspects of disease management
- Provided health education in four domains: dementia as a disease process, behavioral and psychological symptoms, medical comorbidity, and caregiver concerns

(Lessig et al., 2006)

Cooperative Dementia Care Clinics

Modes of practice of CDCC

- A shared medical appointment among patients, family members, geriatric psychiatrist, general physician and social worker
- Signed a confidential agreement by patients and their family members
- Limited to six to eight pairs with a 2-hour time frame
- Involved healthcare portion (in round table examination), educational portion (identified in advance or arising during the course of group care)

Cooperative Dementia Care Clinics

Sample interventions of CDCC

- Medication prescription for dementia or behavioral and psychological symptoms
- Referral to day care or respite services
- Change of diagnosis
- Managing diseases other than dementia
- Educational talks
- Counseled to resolve family conflicts

(Lessig et al., 2006)

Cooperative Dementia Care Clinics

Sample interventions of CDCC

- Samples educational topics:

Domains	Medical/psychiatric	Behavioural/psychosocial
Dementia as a disease process	Type of dementia Dementia medication	Managing communication problems
Behavioural and psychological symptoms	Why they happen Psychotropic medications	Caregiving training: Managing difficult behaviors and mood
Medical comorbidities and functional risks	Dehydration Fall prevention	Preventing hospitalization
Caregivers concerns	When to consider antidepressant medications Becoming an effective healthcare advocation	Asking family for help or hiring professional caregivers

(Lessig et al., 2006)

Cooperative Dementia Care Clinics

Perceived benefits from clinician perspective (based on observations)

- Fewer dementia-related emergencies and non-acute interval phone calls
- Fewer prescription lapses
- Timely visit scheduling
- Less need to repeat the same educational materials

(Lessig et al., 2006)

Cooperative Dementia Care Clinics

Perceived benefits from caregivers' perspectives

- Expressed satisfaction by caregivers and patients
- Felt being supported
- Increased their understanding of dementia management
- Combined medical care with support group functions

(Lessig et al., 2006)

Cooperative Dementia Care Clinics

Conclusive remarks

- Regards as an alternate approach in increasing dementia care capacity in primary care settings
- Especially for those with medical complex, dementia patients
- Subjective comments from clinician and user perspectives and have not been tested empirically
- Limitations of the model: Requires good clinical and communication skills; not all patients interests in this model, and embarrassment in discussing sensitive issues

Partnership between Managed care (MC) and Alzheimer's Association (AA) in US

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Partnership between MC and AA

Background of the program

- Philosophical base of managed care in US:
  1. Providing health information and support services to prevent crisis episodes and excess utilization
  2. Helping patients to cope with illness
- Providing these non-medical services for those with multiple chronic conditions or frequent hospitalization and emergency room visit only
- As an innovative approach by partnership of a managed care health system with community agencies to maintain the services
- Pioneered project by partnership of Kaiser Permanente of Ohio and the Cleveland Area Alzheimer's Association

(Bass et al., 2003)

Partnership between MC and AA

Partnership as an intervention

- Incorporated the concept of care consultation in the project
- Based on the framework of empowerment that patients and their family members could make their own decision provided that sufficient information is given
- Care consultation was offered by 3 licensed social workers from the Association

(Bass et al., 2003)

Partnership between MC and AA

Partnership as an intervention

- Goals of consultation: (1) provided tools to enhance patients' and caregivers' competence and self-efficacy, (2) provided information on community services, facilitated their decision making, and assisted them to contact agencies
- Free of charge to use all association services
- Care consultants needed to follow standard protocols for service delivery

Partnership between MC and AA

Duties of care consultants

- Initiated the first contact with patients and family caregivers
- Conducted a structured initial assessment
- Formulated ICP (problems identification and strategies formulation)
- Collaborated with patients and family caregivers
- Offered support services (from the Association) to patients and family caregivers
- Conducted reassessment
- Arranged regularly follow-up depending on the needs but scheduled to have 12 direct communication contacts per year

(Bass et al., 2003)

Partnership between MC and AA

Empirical evidence of the partnership

- Research design: Randomized trial in 12-month study
- Target participants:
  - Received managed care from Kaiser
  - Either a specific diagnosis of dementia or memory loss in medical record
  - 55 years old or above
  - Not living in residential settings
  - Lived in service area of the Cleveland Area Alzheimer' Association

(Bass et al., 2003)

Partnership between MC and AA

Empirical evidence of the partnership

Outcome variables:

Utilization outcomes	hospital admission, emergency department visits, physician visit, Kaiser case management visit, direct care community services, & non association information and support service
Satisfaction with health plan by caregivers	satisfaction with (1) types of Kaiser service, (2) quality of Kaiser service, and (3) information received about illness
Caregiver outcomes	depression, relationship strains, health deterioration, and role captivity

(Bass et al., 2003)

Partnership between MC and AA

Results and conclusion

- A promising strategy
- The approach resulting in
  - lower utilization of managed care, direct care community services, and non-Association information support service
  - higher level of satisfaction towards managed care services
  - lower level of depression and strain

(Bass et al., 2003)

Partnership between MC and AA

Results & conclusion

- The effect of the approach intensified if
  1. care consultation is used in junction with other Association services;
  2. Older people have not been diagnosed as a dementia;
  3. memory difficulties of older people are more severe;
  4. caregivers are non-spousal

(Bass et al., 2003)

Specialist Home Care Services for Older People with Dementia in UK

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Specialist home care services

Background of the SHCS

- Standard home care was perceived as task-oriented and was criticized as inappropriate for older people with dementia
- SHCS was introduced in Nottingham (UK) in 1999
- Aims at reducing high level of care home placement & responding to statutory inspection recommendations by UK government

(Rothera, et al., 2008)

Specialist home care services

Structure and function of the services

- Careworkers with additional training in dementia care
- Performed tasks flexibly: conducting visits outside clients' home, providing respite service, or changing staff roster to maximize the continuity
- Weekly meeting covered debriefing, supervision and support from a service manager, OT, and CPN
- Addressed on clients' overall needs, requirements and preferences instead of physical care tasks

(Rothera, et al., 2008)

Specialist home care services

Structure and function of the services

- Supported by a multi-disciplinary health and social service team
- Care plan focused on “needs-led” instead of “provider-led”
- Monitored clients’ needed closely and adjusted the care plan if appropriate
- A waiting list was operated when the team capacity was reached

Specialist home care services

Key characteristics of SHCS

- Adopted the biopsychosocial model as their philosophical base (focus on identity, role and individuality of the persons with dementia)
- Formation of long-term client-careworker relationship was important
- Caregivers being actively involved in the caring process and taking part in decision making

(Rothera, et al., 2008)

Specialist home care services

Key characteristics of SHCS

- Identified needs of caregivers/demented older people and formulated an agreeable care plan between case worker and caregivers to address the needs
- Careworkers followed through their responsible clients to promote the continuity of care
- Flexible work schedule for the careworkers in order to address the needs of clients in each day

(Rothera, et al., 2008)

Specialist home care services

Key characteristics of SHCS

- Clear referral system to the service with no admission waiting list
- Specialized training to all staff (ongoing and cumulative)

(Rothera, et al., 2008)

Specialist home care services

Comparison study of generic and specialist HCS

- Used UK national minimum standards to compare the generic and specialist HCS
- 65 service users of generic HCS and 10 service users of specialist HCS joined in the study

(Venables, et al., 2006)

Specialist home care services

Results

- Systematic assessment: generic HCS performed better than specialist HCS in keeping briefing documents in user's home only
- Flexibility : generic HCS performed better than specialist HCS in 24-hour service & live-in-service provided if necessary, and day and night care (7days a week)
- Integration: specialist HCS performed better than generic HCS in accommodation, and management

(Venables, et al., 2006)

Specialist home care services

Results

- User-centred practice: specialist HCS performed better than generic HCS in formal arrangements for providing support to friend/relatives the use of memory/life story wallets
- Cultural appropriate care : no apparent difference
- Staff training: no apparent difference

(Venables, et al., 2006)

Specialist home care services

Conclusions

- Tailors the specialist HCS to meet the specific needs of carer/older people with dementia
- Operationalizes the principles of person care approach into the specialist HCS
- Built in flexible, individualized, and continuity care features in service designs
- Cautions in interpreting the results of the comparative study because of small sample size in specialist HCS
- Pending for a study with more representative samples

Feasibility of adopting the new care practices in Hong Kong context

Feasibility: Cooperative Dementia Care Clinics

Applicability:

- May apply the service model in memory clinics in Hong Kong

Advantages:

- Expands the scopes of services in clinics
- Serves more clients
- Expertised from the clinics
- Provides one stop service (from assessment to intervention),

Feasibility: Cooperative Dementia Care Clinics

Issues need to be resolved:

- Issues of confidentiality
- Openness of caregivers/older people with dementia to discuss sensitive issues
- Additional human resources
- Limited no. of memory clinics in Hong Kong
- Stigmatization of service users…

Feasibility: Partnerships between MC and AA

Applicability:

- Managed care system is not common in Hong Kong at this moment. In addition, such kind of AA is not common in Hong Kong. May consider to adopt the service model to older people with memory problems in District Elderly Community Centre (DECC) with the collaboration with Hong Kong Alzheimer's Disease Association (HKADA) or Jockey Club Centre of Positive Ageing (JCCPA)

Feasibility: Partnerships between MC and AA

Advantages:

- Early detection of older people with memory difficulties in community level
- Provides early supportive intervention to older people with memory problems

Issues need to be resolved:

- Collaboration between DECC and HKAA, additional dementia care training for professionals as care consultants, may beyond the service scopes of DECC…

Feasibility: Specialist Home Care Service

Applicability:

- May apply the service model in the Enhanced Home Care and Support Services in Hong Kong

Advantages:

- Specialized services tailor to the needs of older people with dementia and their caregivers and decrease the needs of residential settings

Feasibility: Specialist Home Care Service

Issues need to be resolved:

- More intensive training for professional and care staff
- Requires additional human resource
- No limits in the capacity of the service
- Collaboration with other agencies or service centres

Summary of chapter

- Characteristics and empirical evidence of three innovative dementia care programs/practices that are originated from western countries have been described

- The feasibility of adopting the new care practices in Hong Kong context has been discussed individually

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The End of Chapter 7