

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

CTP 004 – Dementia: Preventive and Supportive Care

## Web-based Course for Professional Social and Health Care Workers

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# Chapter 9:

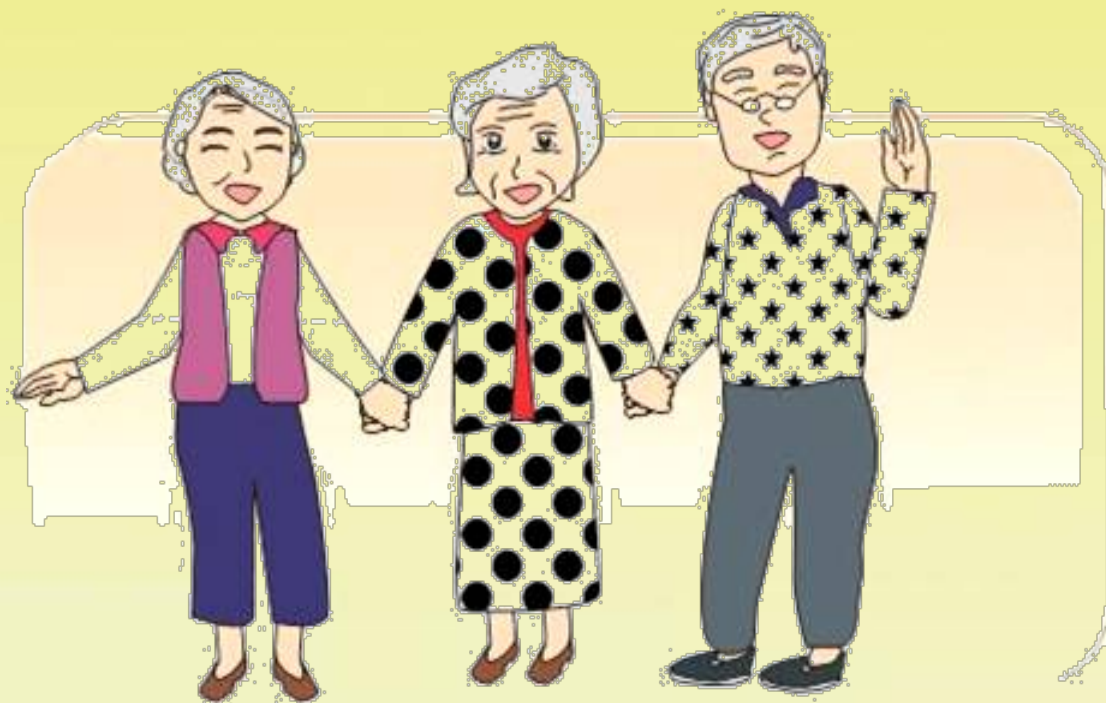
## Community Care and Social Services for Dementia: Individual and Caregiver Perspectives



# Content

- Holistic community services for older adults with dementia: From evaluation to supportive care
- Holistic community services for caregivers of older adults with dementia
- The role and importance of community care and social services to the well-being of people with dementia and caregivers: The users' perspectives

# Holistic community services for older adults with dementia: From evaluation to supportive care



# Overview of Community & Support Care Services for Older Adults with Dementia

## Evaluation Services

- General Practitioners
- Private Psychiatrists / psychogeriatrists

- Memory clinic
- Early detection services offered by NGOs



Depends on the needs of older adults with dementia and their caregivers, and impairment level of the older adults

## Community & Support Care Services

Short-term  
•Respite

### Long-term

- Day care service
- Enhanced home and community care services
- Integrated home care services (frail cases)

# Community Services – Older Adults with Dementia

## Memory Clinics

- 9 memory clinics (e.g. Castle Peak Hospital, Queen Mary Hospital, Ruttonjee Hospital, Kwai Chung Hospital and United Christian Hospital)
- Under the operation of Hospital Authority
- Aim at providing clinical diagnostic service for older adults with suspected dementia or memory problems
- Medical referral is required





# Community Services – Older Adults with Dementia

## Early Detection Services

- Aim at early detection of older adults with mild cognitive impairment or the early stage of dementia
- Is provided by
  - the Hong Kong Alzheimer's Disease Association (HKADA) and
  - the Jockey Club Centre of Positive Ageing (JCCPA)
- No referral is required but needs to fill in an application and make appointment
- Cost of the service:
  - \$300(Regular) or \$450 (Express) in HKADA
  - \$450 in JCCPA

(HKADA, 2011a; JCCPA, 2011a)

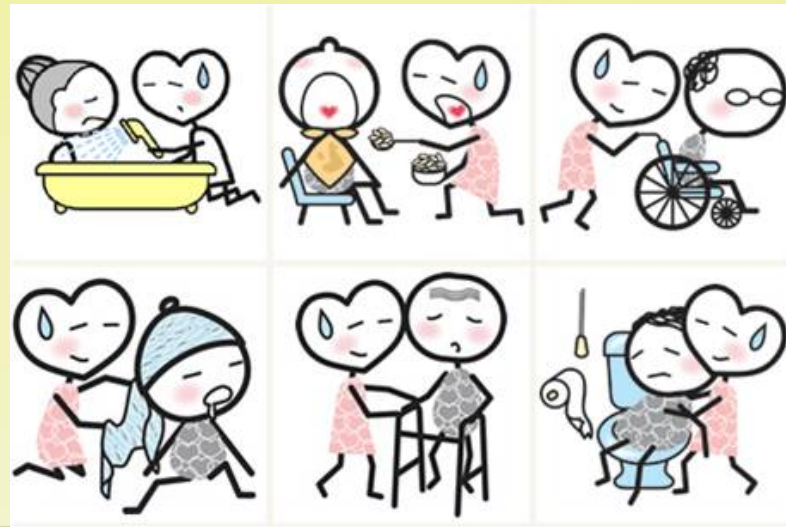


# Community Services – Older Adults with Dementia

## Home Care Services

- Aim at providing nursing, rehabilitation, and supporting services in order to enable frail older adults continuing living in their familiar environment
- Divide into two types:
  - Integrated Home Care Services (ordinary and frail case), and
  - Enhanced Home and Community Care Services (EHCCS)
- Service allocations depend on the frailty of older adults as determined by results of the Standardized Care Need Assessment Mechanism for Elderly Services

(Social Welfare Department, 2005a)





# Community Services – Older Adults with Dementia



## Home Care Services

- Assessment done by the accredited assessors from HA, NGOs, or Social Welfare Department who have received training in Minimum Data Set-Home Care
- 60 IHCS teams and 24 EHCSS teams in Hong Kong that are operated by NGOs
- Provide in home training services, meal service, assistance in personal care & routine household chores, rehabilitation services, and nursing care to demented elderly
- Staff composition: social worker, nurse, OT or/and PT, home care workers

(Social Welfare Department, 2012a)

# Community Services – Older Adults with Dementia

## Day Care Services

- provide a wide range of daytime support services to enable demented older adults suffering from moderate to severe level of impairment to maintain their optimal level of functioning, develop their potential, improve their quality of life and to live in their own homes if possible (SWD, 2008c)
- 59 day care centres and units that run by NGOs in Hong Kong
- Include personal care, social/recreational activities, nursing care, rehabilitation programs, meals, health education, and transportation

(Social Welfare Department, 2012b)

# Community Services – Older Adults with Dementia

## Day Care Service

- Full-time service (4 days or more/week) for elders with low self care abilities or lack of carer in day time or part-time service (less than 4 days/week) for elders with high self-care abilities
- Older adults aged 60 or above with moderate or severe impairments as determined by the Standardized Care Need Assessment Mechanism for Elderly Services
- Day care services that are specialized in dementia care are offered by HKADA, & JCCPA



(HKADA, 2012b; JCCPA, 2012b; Social Welfare Department, 2012c)

# Community Services – Older Adults with Dementia

## Respite

- Provides a short-term day care or overnight service to older adults with disabilities
- No need to go through the Standardized Care Need Assessment Mechanism for Elderly Services
- Offers by private nursing homes, care and attention homes, day care units, JCCPA and Cheung Muk Tau Holiday Centre for the Elderly
- Contacts the individual unit/centre in advance

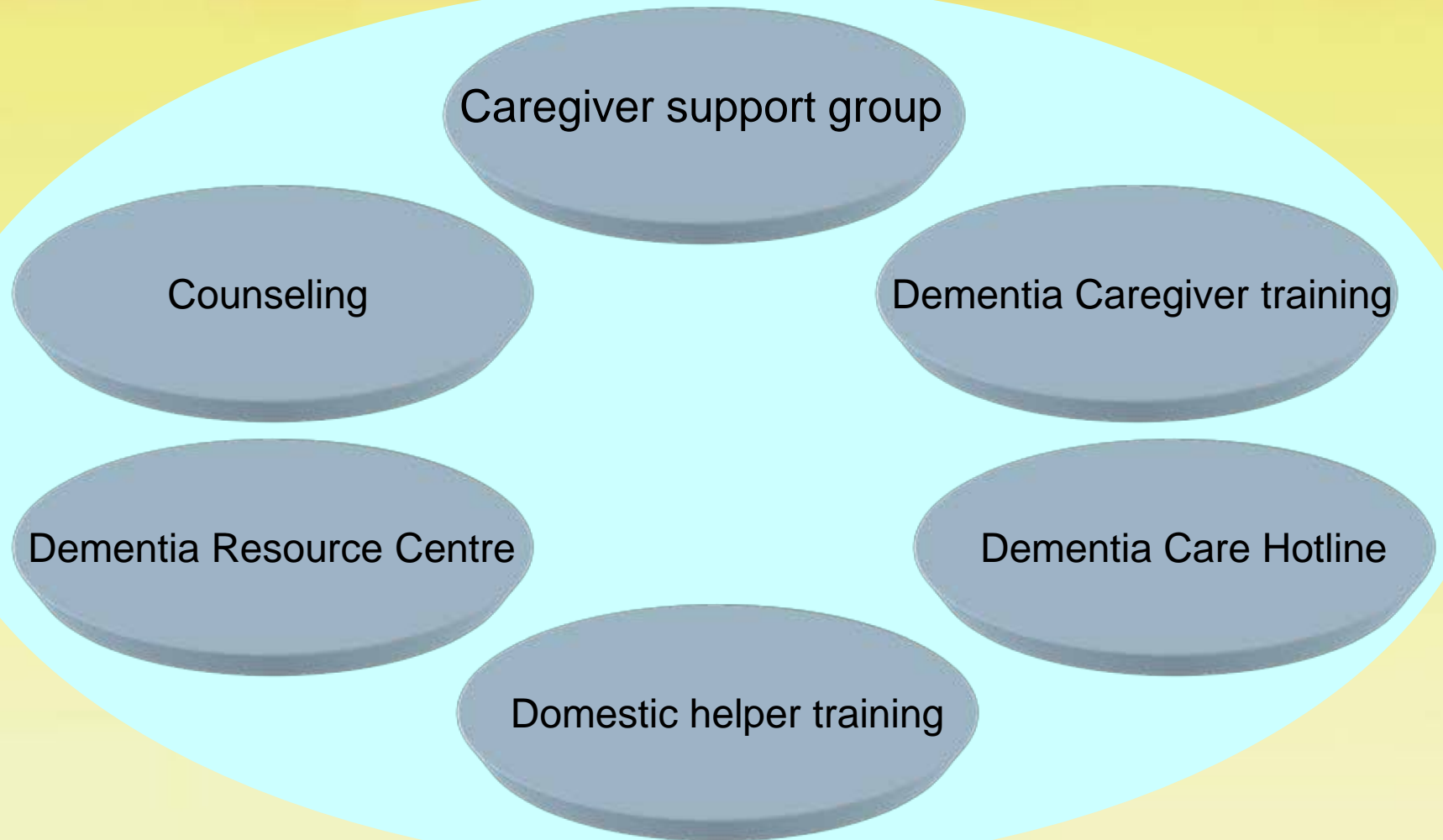
(JCCPA, 2012c; Social Welfare Department, 2012d)



# Holistic community services for caregivers of older adults with dementia



# Overview of Community and Support Care Service for Caregivers





# Community Service - Caregivers

## Dementia Caregiver Training

- Usually conducted in forms of home visit and educational talks by professional staff
- Aims at sharpening their caring skills and promoting the quality of life of caregivers and the demented older adults
- A wide range of topics such as illness of dementia, impact of dementia, daily caring, communication skills and community services
- Formal public training courses are mainly provided by the JCCPA and the HKADA, or psychogeriatric teams of HA and NGOs

(HKADA, 2012c; JCCPA, 2012d)



# Community Service - Caregivers

## Counseling

- Provides an emotional support for caregivers and facilitates them to cope with burnout
- Reduces the caregiver stress and burden
- Offers by all day care units, IHCST, EHCCSS, and HKADA

(HKADA, 2012d; Social Welfare Department, 2012d)



# Community Service - Caregivers

## Caregiver Support Group

- Provides an emotional support and promotes a mutual support among caregivers together with educational health
- Aims at reducing caregivers' stress and improving quality of care
- Specific dementia support groups offer by the HKADA, the JCCPA or some NGOs

(HKADA, 2012e; JCCPA, 2012e)



# Community Service - Caregivers

## Dementia Resource Centre

- Provides specific educational resources in dementia, including books, magazines, Newsletter, & audio-visual material
- Offers by the HKADA and the JCCPA
- Requires membership fee in some centres  
(HKADA, 2012f; JCCPA, 2012f)



# Community Service - Caregivers

## Domestic Helpers Training

- Caring duties relieved by hiring of domestic helpers
- Aims at enhancing caring skills of foreign domestic helpers in taking care of frail older adults
- Two types of training course
  1. focus on teaching basic self-care skills and essential skills (by the Hong Kong Institute of Gerontology)
  2. Specially tailor for helpers to take care of elderly with cognitive impairment (by the JCCPA)

(Hong Kong Institute of Gerontology, 2010; JCCPA, 2012g)



# Community Service - Caregivers

## Dementia Care Hotline

- Aims at providing a channel for caregivers to require information, make inquiry, seek helps in crisis, and request referral
- Dementia care hotline offers by the HKADA

(HKADA, 2012g)





The users' perspectives:  
The importance of community care and  
social services to the well-being of people  
with dementia and caregivers



# Users' Perspectives

- Who is/are the user(s) in informal care of older adults with dementia?
  - A. older adults with dementia
  - B. family caregivers
  - C. domestic helpers
  - D. all of the above



# Users' Perspectives

The importance of understanding of the users' perspectives towards the community care and support service:

- Addresses the needs of users (more customer driven)
- Bridges the service gap
- Service improvement
- Improves the quality of life of users

# Users' Perspectives

## How do you solicit the perspectives of users?

Family caregivers:

- Interview
- Survey
- Focus group...

Older adults with dementia:

- Is it possible?
- If so, how?

# Users' Perspectives

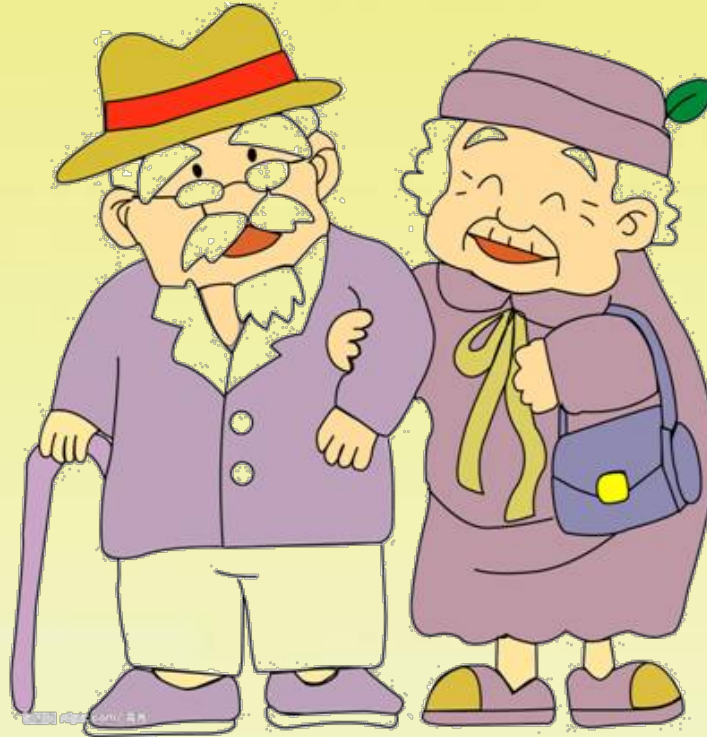


## Practical tips for eliciting perspectives from older adults with dementia

- Semi structured interview with open ended broad questions
  1. Being sensitive to avoid the exacerbation of their emotional states
  2. Present faces with different expressions (three in total - happy, neutral, and sad emotion) during interview
  3. Video taped the discussion with demented individuals who have verbal difficulty in order to observe their non-verbal response
- Interview with next of kin
- Observation or video tape of the daily life of people with dementia

(Aggarwal et al., 2003; Hubbard et al., 2003)

# Caregivers' Perspectives in Western Countries





# Caregivers' Perspectives (Western Countries)

## Caregivers of people with dementia in foreign studies

- Mainly solicits the perspectives of caregivers of older adults with dementia for exploring the reasons of service utilization
- More likely to employ the approach to contrast the caregivers who use and don't use the community service



# Caregivers' Perspectives (Western Countries)

## Reasons of not using community services

- Four major categories identified in literature review by Brodaty et al. (2005) that accounted for why caregivers of older adults with dementia did not use services:
  1. Services not needed
  2. Reluctant to use services
  3. Service characteristics impede use
  4. Do not aware of the services



# Caregivers' Perspectives (Western Countries)

## 1. Service not need:

- Caregivers thought that they could manage at the moment
- Received adequate social support

(American Association of Retired Persons, 1988; Brodaty et al., 2005; OTA, 1987, Caserta et al., 1987; Brody et al., 1989; Cotrell, 1991; Miline et al., 1993; Opie, 1991)



# Caregivers' Perspectives (Western Countries)

## 2. Reluctant to use service:

- Denial of need
- Invasion of privacy
- Did not want interferences from others
- Feared of loss of role
- Rejection by care recipient



(Brodaty et al., 2005; Brody et al., 1989; Caserta et al., 1987; Collins et al., 1991; Hamilton et al., 1996; Levesque et al., 2000; Miline et al., 1993; Morgan et al., 2002; O'Connor, 1995; OTA, 1987; Ortiz & Fitten, 2000; Twigg & Atkin, 1994)

# Caregivers' Perspectives (Western Countries)

## 3. Service characteristics impede use

- Lack of knowledge about the eligibility and appropriateness of service
- Inappropriate for their needs
- Service not cultural sensitive
- Services not available
- Inconvenient hours of operations
- Concerned about the quality of care
- Cost of service



(American Association of Retired Person, 1988; Beisecker et al., 1996; Brodaty et al., 2005; Caserta, et al., 1987; Collins et al., 1994; Cotrell, 1991; Dellmann-Jenkins et al., 2000; Gill et al., 1998; Hamilton et al., 1996; Morgan et al., 2002; Orcher, 1995; OTA, 1987; Twigg & Atkin, 1994)

# Caregivers' Perspectives (Western Countries)

## 4. Do not aware of the services

- Did not know about services
- Lay outside the service system
- Regarded dementia as a normal ageing process by certain ethnic groups
- Language barriers
- Stigmatization on people with dementia

(Brodaty et al., 2005; Mistic, 1996; Papanicolaou & Fitch, 1996; Tebb & Jivanjee, 2000; Toseland et al., 1999)





# Caregivers' Perspectives (Western Countries)

## Service seeker and non-seeker of respite service

- Another study attempted to identify factors to account for why caregivers of Alzheimer's patients sought for respite service by comparing service seeker and non-seeker
- Seeker was defined as those who inquiry about respite service
- Significant predictors to be service seekers:
  - High level of caregiving burden
  - Being the single caregiver for the client
- None of variables, such as beliefs about personal responsibility and aspects of service delivery was predictive factor of service seekers



(Kosloski et al., 2001)

# Users' Perspectives in Hong Kong



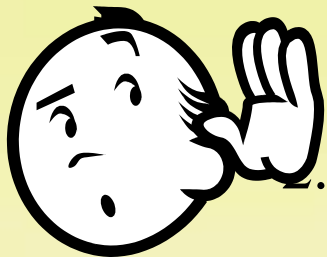
# Users' Perspectives in HK

## What about the perspectives of caregivers and care-recipients in Hong Kong?

- Due to limited local study in this area, insights will be gained by referencing several local studies that look into

1. needs of older adults with chronic disabilities  
(even though there is a local study to look into the care needs of older adults with dementia)

2. needs of caregivers of older adults with disabilities



# Perspectives of older adults with dementia and chronic disabilities



# Care-recipients' Perspectives (HK)



## Care needs of older adults with dementia

- 197 community dwelling older adults with dementia (mild to severe impairment) were assessed using the Chinese version of the Care Needs Assessment pack for Dementia (CarenapD)
- Greater than 70% of participants were identified as having 'no' care needs in 29 out of 57 items, including
  - Health and mobility (getting in/out of chair and bed, hearing)
  - Self care (urinary and faecal incontinence, dental care, washing themselves)
  - Behaviors and mental state (difficult sexual behaviors, physical aggression, verbal aggression, wandering),
  - Household management (doing housework, doing laundry, using air-conditioner, using cookers, safety with appliance, and gas)
  - Community living (taking medication, ability to make snacks and drinks, smoking and drinking alcohol appropriate)



# Care-recipients' Perspectives (HK)

## Care needs of older adults with dementia

- 'Unmet' care needs were found in 10 items from 4 domains
  - Healthy and mobility (hearing)
  - Social interaction (activity participation, understanding others, and expression of needs)
  - Thinking and memory (recognizing strangers' roles, repetitive questioning, and memorizing daily routines)
  - Behaviour and mental state (wandering, restless/agitated, sad/worried, and unstable mood)
- Care needs of persons with increasing severity of cognitive impairment shifted, for example, participants in the middle and late stages of dementia required assistance and support and/or showed unmet care needs for the performance of self-care activities.



(Chung, 2006)

# Care-recipients' Perspectives (HK)

## Perspectives of care-recipients towards formal service

- A quantitative study that involved 340 older adults with chronic illness who were drawn randomly from 18 administrative regions in Hong Kong
- Care-recipients' knowledge/use of community services were as follows:

	with knowledge (Yes)	use of service (Yes)
Hospital	93.7%	38.3%
General clinics	95.8%	66.4%
Specialist clinics	94.4%	68.0%
Home help	92.0%	74.8%
Community services	64.3%	26.4%
Day care centre	44.7%	9.2%
Day hospital	36.7%	5.9%
Self-help group	26.6%	9.8%
Social networking	26.5%	12.1%



(Division of Social Studies, City University of HK, 2003)



# Care-recipients' Perspectives (HK)

## Needs of care-recipients for professional care

- At the same study, care recipients' needs and reception of professional care were also solicited:

	Needs (Yes)	Reception (Yes)
Professional care	88.3%	45.7%
Daily living	88.7%	62.1%
Reassurance	87.5%	31.6%
Leisure activities	89.0%	35.4%



(Division of Social Studies, City University of HK, 2003)

# Care-recipients' Perspectives (HK)

## Determinants of care utilization by care-recipients

- A cross-sectional study that involved 702 community dwelling older adults in Kwun Tong and Tseung Kwan O districts of Hong Kong.
- Aims at exploring the health and care utilization patterns of older adults



### Results:

1. Suffering from at least one type of chronic disease
2. Feeling that no one can help

were the predictive factors of formal care utilization by older adults

(Liu et al., 2001)

# Insights from care-recipients' perspectives (HK)

- The voices of older adults with dementia have been overlooked in local literature
- More familiar with medical and instrumental services, such as clinics and hospital as compared with community care support services.
- Under utilization of community care support services by older adults with or without chronic illness.
- Majority of care-recipients indicates needs of various care services but only a few of them received it, especially in the aspects of emotional support and leisure participation.
- Care-recipients with complex health conditions and having a weak social support are more likely to turn to formal services



# Perspectives of family caregivers of older persons with dementia



# Caregivers' Perspectives (HK)

## Service utilization of caregivers

- A survey study that involved 115 caregivers of older adults with chronic illness living in a public estate in Tseung Kwan O
- Conducted in form of home visit

### Results:

- Service utilization by the caregivers
    - Only 13% of caregivers had used home care and support service
    - Only 9% of caregivers had used community nursing service
    - Only 16% of caregivers used caregiver support service
  - Major reasons of the under utilization
    - No need of formal service (72.7% of caregivers)
    - Lack of knowledge on community resource (13.4% of caregivers)
- (聖公會將軍澳安老服務大樓, 2004)

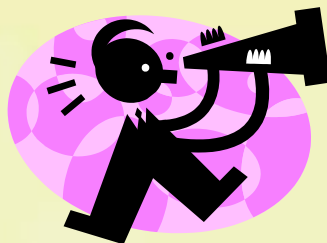


# Caregivers' Perspectives (HK)

## Future needs of community care services

- In the same study, the caregivers of older adults with chronic illness indicated their future needs of community care services:

	aged below 60	aged above 60
Introduction of community resource	64.3%	46%
Telephone hotline service	53.6%	34.5%
Financial support	32.1%	32.1%
Respite service	57.1%	17.2%
Caring skills and techniques	39.3%	27.6%
Advice in decision making	50%	26.4%
Emotional/psychological support	46.3%	25.9%
Emotional/psychological support to care-recipient	39.3%	23%



(聖公會將軍澳安老服務大樓, 2004)

# Caregivers' Perspectives (HK)

## Perceived effectiveness of community care

- A quantitative study that involved 340 older adults with chronic illness who drawn randomly from 18 administrative regions in Hong Kong
- 153 caregivers of older adults were also interviewed
- Results: % of caregivers who perceived effectiveness in different modes of care services



Family in maintaining elders' health	57.8%
Family in making elders happy	63.7 %
Hospital in maintaining elders' health	60.5 %
Hospital in making elders happy	47.0 %
Community care in maintaining elders health	54.9 %
Community care in making elders happy	56.8 %

(Division of Social Studies, City University of HK, 2003)



# Caregivers' Perspectives (HK)

## Perspectives of caregivers towards formal service

- A qualitative study that involved interviewing 6 older adults with chronic illness, 6 family caregivers, and 6 formal caregivers in Kwun Tong
- Results from family caregivers' perspectives toward formal care services:
  - Regarded the formal care services as both substitution and complement of informal care
  - Viewed as a quality service
  - Had a high level of confidence on professional care
  - Reduced caring burden by formal service
  - Built up trust with formal caregivers



(Asia-Pacific Institute of Ageing Studies & Christian Family Service Centre, 2004)

# Insights from caregivers' perspectives (HK)

- The perspectives of caregivers of older adults with dementia have been largely overlooked in local literature.
- Similar to western countries, the community care and support services are under utilized by the caregivers
- Caregivers generally agree the quality of care in the community care and support service but perceive that family care and hospital care as the best of care for older adults in promoting their happiness and health respectively.



# Insights from caregivers' perspectives (HK)

- Young and older caregivers indicate different future needs of community services. For example, younger caregivers demand for information on community resources, telephone hotline services, respite services whereas older caregivers demand for information on community resources, telephone hotline services, and financial support.



# Strategies in promoting service use

- Increases community awareness on the availability of services
- Normalizing service-use
- Destigmatizing dementia
- Makes referral to service by professionals
- Facilitates the access of service
- Choices of service

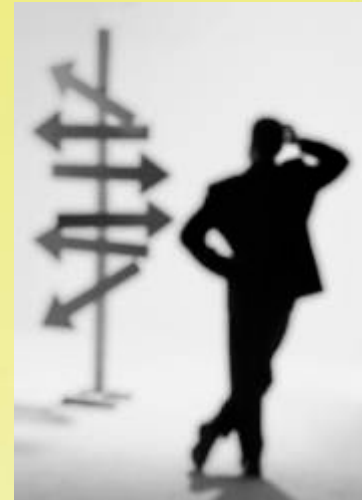
(Brodaty et al., 2005)



# Examples of choices of respite services in US

- Host family overnight respite
- Overnight stays at day centres
- Social outings as a form of respite
- Holiday programs
- Respite provided with intensive carer education and support
- Day centre with extended hours
- Day centre runs in conjunction with in-home respite
- In-home occasional or emergency respite

(Shanley, 2006)



# Examples of choices of respite services in US

- Residential respite in a non-institutional setting
- Day respite offered by a nursing home
- Mobile respite service
- Respite combined with providing something special for the carers
- Respite through a leisure buddy system



(Shanley, 2006)



# Summary

- Community services that range from evaluation to supportive care for older adults with dementia and their family caregivers in Hong Kong are introduced
- Four main reasons that family caregivers did not using community services in foreign literature are stated
- The perspectives of older adults with chronic disabilities and their family members in local literature are highlighted
- Multiple strategies that promote the use of community care service are introduced





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