

The 10th International Conference on Grief and
Bereavement in Contemporary Society (10th ICGB)

EAST MEETS WEST Expanding Frontiers and Diversity

June 11 – 14, 2014 | Hong Kong



Supporting the Family as a Whole

A Needs Assessment Study on Cancer Families in Hong Kong

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11 June 2014



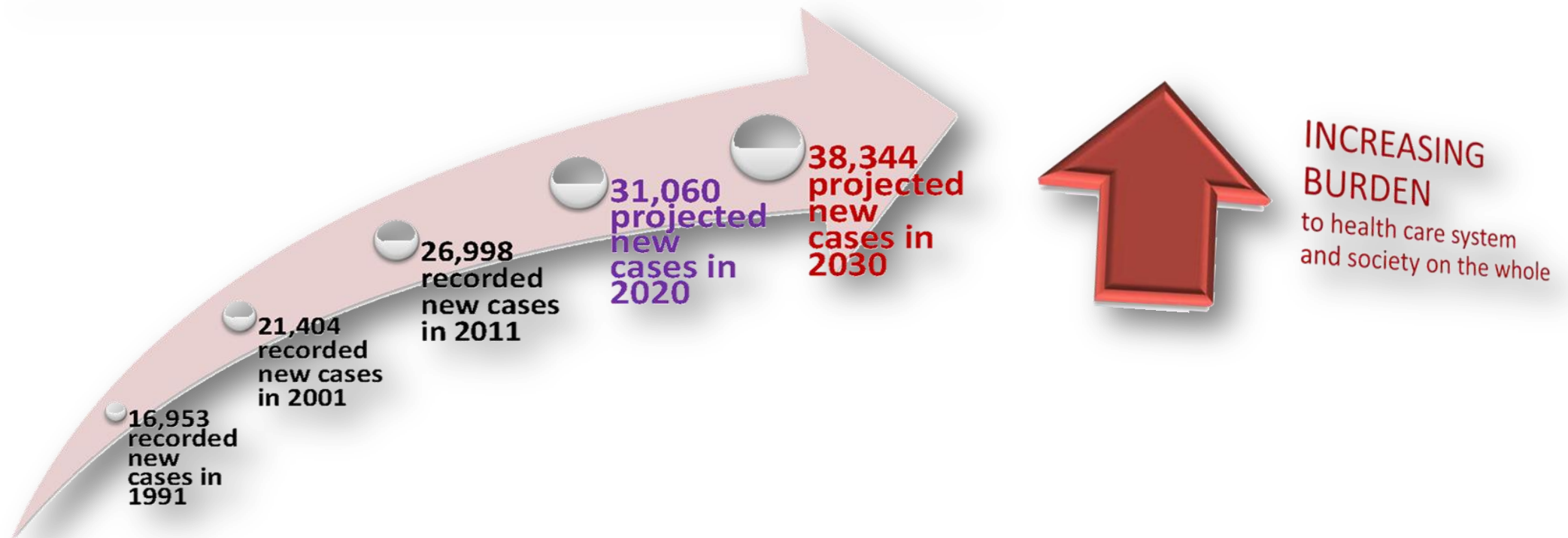
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THE HONG KONG ANTI-CANCER SOCIETY

Since 1963

Background

- Increasing cancer burden in the next 20 years.
- In 2011, there were 26,998 new cases of cancer and it is projected to rise to 31,060 in 2020 and 38,344 in 2030!



Background

- In HK, majority of cancer patients are treated & followed-up in an outpatient setting. Patients are expected to care for themselves with the help of their families or others throughout treatment and rehabilitation.
- Cancer adds extra strain on patients and caregivers emotionally, psychologically and financially.



Caner is a Family Disease

Reciprocal suffering: Patients and families are
“inextricably interrelated as the suffering of one amplifies the distress of the other” (Sherman,1998)



Background

- Some industrialized countries have invested resources to provide family-based community cancer care for patients and their informal caregivers.
- In HK, little is known of the health needs of cancer patients and their family caregivers, let alone the provision of comprehensive family cancer care.






“Need is ... the gap between current status and expected or desired status.”

(Kaufman & English, 1979)



Aims of the Study



better
understand the
needs of the
cancer families

compare
international
best practices
with local cancer
support services

identify service
gaps

recommend for
development of
cancer support
service in HK



Design of the Study

Research

Quantitative analysis
on the health status of community
cancer patients & care-givers

Qualitative analysis
on the experiences of cancer patients
and care-givers with local services and
their expressed needs

Review

Overview on international best
practices

Local community cancer support
services

Standardized Questionnaires

1. Short Form Health Survey

- **Physical well-being**: physical functioning, *limitations* on functioning, vitality, bodily pain and general health perceptions
- **Mental well-being**: psychological well-being, social functioning, emotional *distress* and its related limitations on functioning

2. Caregiver Reaction Assessment

- **Negative aspects of care-giving**: financial problems, *disruptions* on daily activities, lack of family support, impact on own health
- **Positive aspects of care-giving**

3. Multidimensional Scale of Perceived Social Support

- **Social support** from family and friends



Quantitative Research

On-line Survey on 231 pairs of community cancer patients and their family care-givers in 2012

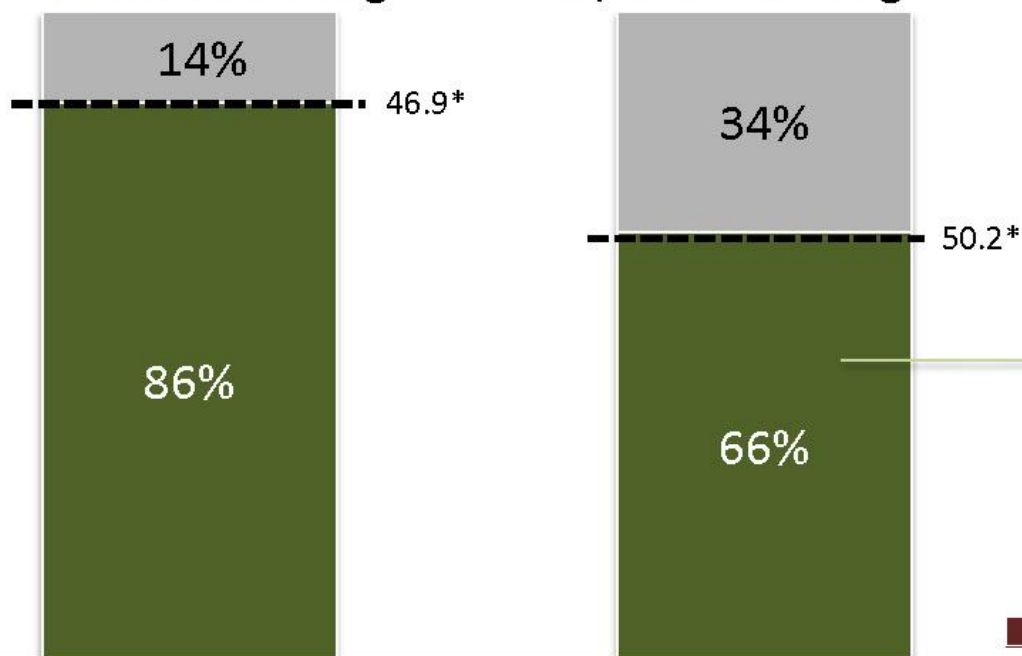


Participants profiles

	Cancer patients n = 231	Family caregivers n = 231
Age in years (mean)	57	54
Gender: Female	59 %	63%
Male	41 %	37%
Cancer Stage: 0-III	68%	
IV	32%	
Years since diagnosis: ≤ 1 yr	63%	
2-4 yr	26%	
5 yr+	10%	
3 main cancer types: Lung	24%	
Breast	19%	
Colorectal	14%	
Relation to patient: Spouse		64%
Son/daughter		14%

Physical well-being

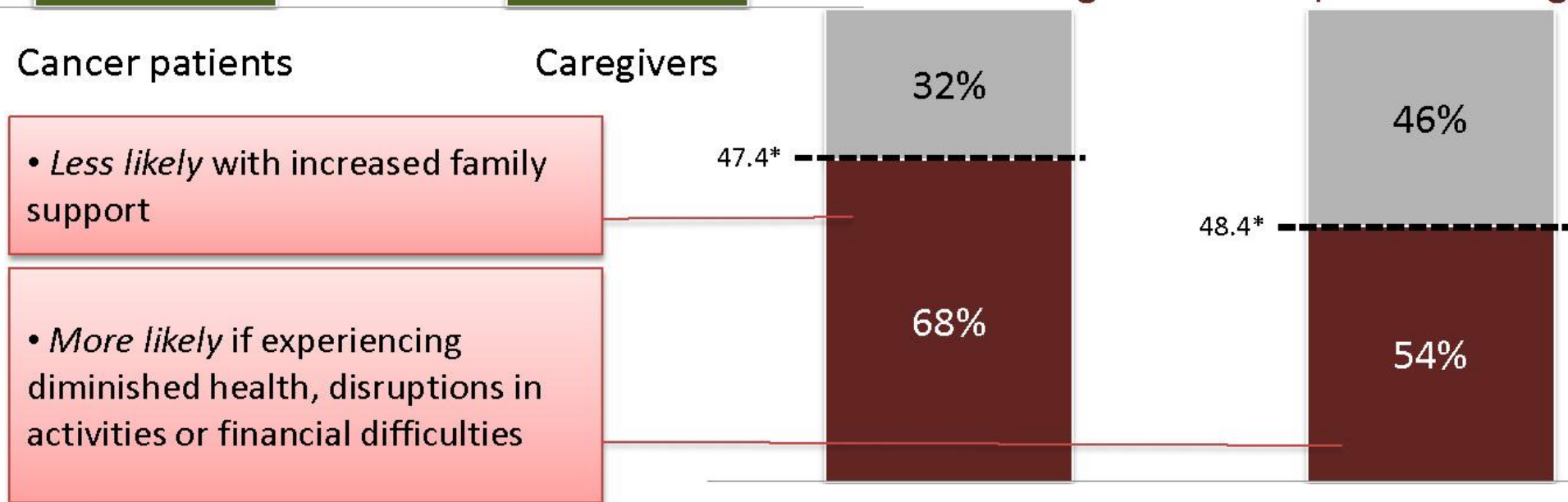
■ Below average ■ At/above average



- More likely if ≥ 60 y^a
- More likely for spouse^b
- More likely if experiencing diminished health

Mental well-being

■ Below average ■ At/above average



- Less likely with increased family support

- More likely if experiencing diminished health, disruptions in activities or financial difficulties

^a & ^b Reference groups = below 40 y & other carers, respectively

*Lam CL, Tse EY, Gandek B. Is the standard SF-12 health survey valid and equivalent for a Chinese population? *Quality Life Res.* (2005) 14:539-547.



Results

1. Most cancer patients and caregivers report low level of physical and mental wellbeing.
2. Majority of patients were limited physically and psychosocially due to health problems.
3. A significant proportion of caregivers had problems with their own health, finances or daily scheduling as a result of caring for the patients.
4. Protective factors in cancer patients against mental distress:
 - Being cared for by their spouse
 - Being supported by family



Results

5. Risk factors in caregivers of physical or mental distress :
 - Being the spouse of patient
 - Being older especially 60 years or above
 - Had health problems, financial problems or experienced disruptions in daily schedule as a result of providing care
6. Male spousal caregivers were more vulnerable to a lack of perceived family support
7. Female spousal caregivers were more affected by patients' mental wellbeing



Qualitative Research

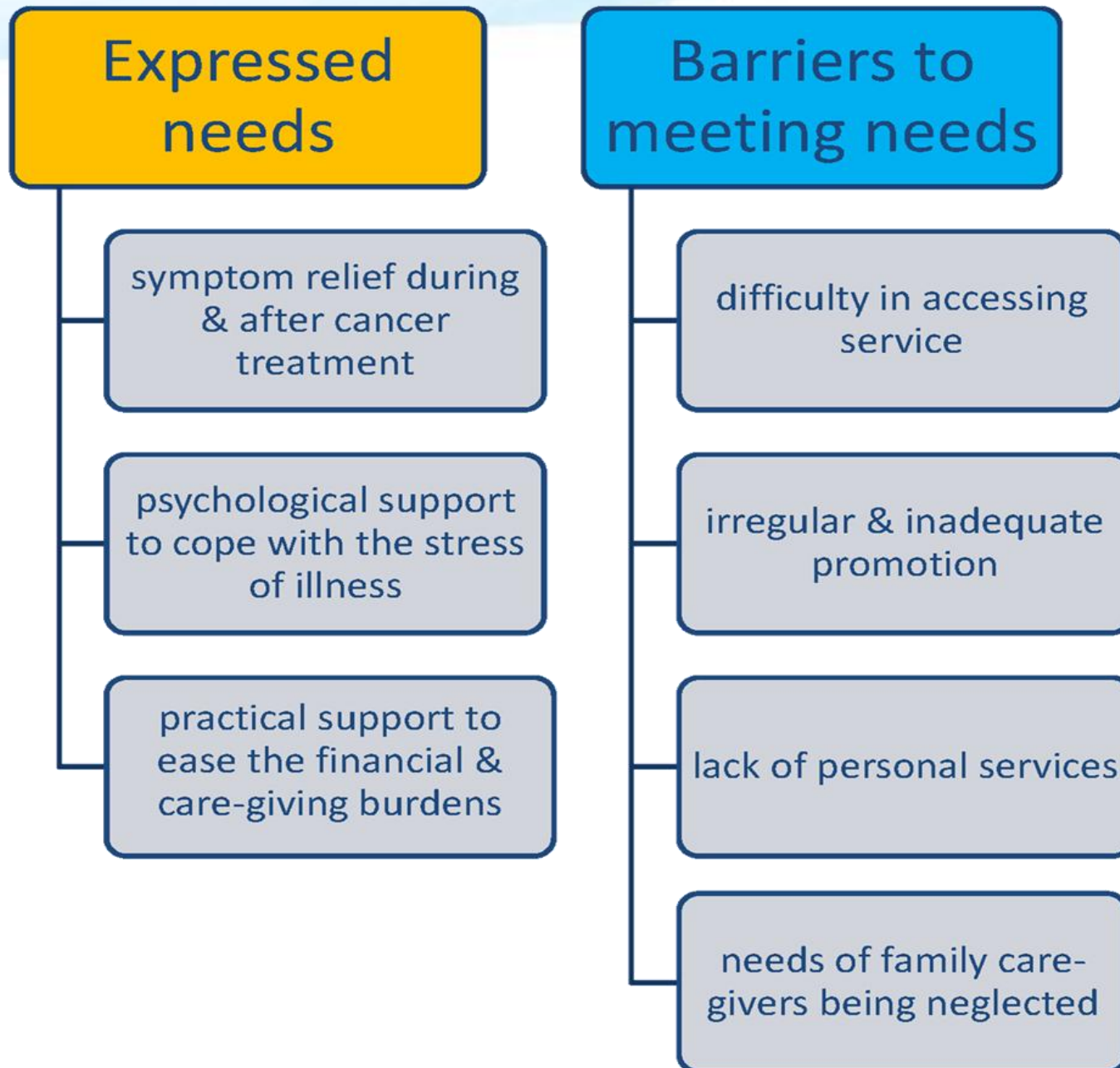
In-depth face-to-face interviews with cancer patients and care-givers in March 2014



Participants Profiles

- 9 cancer patients and 1 spousal caregiver
- Age range of 30 to 70 years
- 3 men and 7 women
- Not currently employed, financially dependent on government subsidies or other family members
- All but one cancer patients had stage III or IV cancer

Patients Expressed Needs





Patients Experience hard to access to services

A 65-year-old man recovering from stage III colon cancer said:

“... some community organizations, they apparently are providing support and services to cancer patients, but in reality, apart from regular newsletters, the practical help is very limited..... difficult to obtain places in their sessions, qigong class or talks... they are always full and do not even provide alternatives....”



Patients Experience

lack of manpower in community centres

A 64-year-old woman with stage IV breast cancer, who needed to care for an aging husband and a mentally disabled daughter, said:

- *“.....all the centres that I have come across so far, had problems with manpower. In one incidence, the worker agreed to escort my husband to a medical appointment because I had to undergo treatment at the same time. However the worker didn't follow up and even turned up on the day.....”*



Patients Experience poor physical health

A 64-year-old woman with stage IV breast cancer, who needed to care for an aging husband and a mentally disabled daughter, said:

- *“Recently, my husband is sick and not able to go to doctor visit with me, then who can go with me? I can only go by myself. doctor prescribed me two huge and very heavy cough syrup bottles, I thought of giving up one of the heavy bottles on my way but I didn't want to waste that. So I tried my best to bring that home. However, I felt very sick when I finally came home...it was so heavy.... ”*



Patients Experience financial problems

A stage IV colorectal cancer patient said:

- *“my poor health has placed tremendous burden on our finance, especially the drug expenses..... each chemo IV costs \$7,000-8,000 ...,*

A stage IV breast cancer patient said:

- *transportation is a problem. Now I take MTR (subway in HK)....how much is a Taxi ride? Can I afford?? No! Many times I felt so sick when I walked down to MTR but I told myself, "you can't pass out, you can't feel sick, you must make it to see doctor"*



Patients Experience nutritional advice

A 65-year-old man recovering from stage III colon cancer said:

- *"Nurse in HKACS suggested me to eat beetroot when my white blood cell count was low. In contrast, staff in some organizations will only say things like "you take care of yourself, eat more nutritious food, etc", advices that really lack of substance and depth, not useful at all..."*



Review

- To review **international best practices** in cancer care and services, experiences drawn from UK, US, Canada and Australia
- Programs and policies relevant to identified needs, including health needs, financial support, daily scheduling and needs to provide family support will be highlighted


Health & Well Being Needs

International Best Practices	Hong Kong
<ul style="list-style-type: none">• Separate action plan/ strategies for cancer care• Separate financial budget/ breakdown for cancer care, increasing health investment• National institute for cancer related research and care services development• Continuous cancer and supportive care extend beyond cancer treatment, implemented by multidisciplinary professionals• Cancer care lead by government and carried out in partnership with community organizations• Cancer services: Information support/ psycho-education, Symptom management and daily care support, Psychosocial support/ interventions, Survivorship care plan, Rehabilitation, and Self help groups/ peer support groups	<ul style="list-style-type: none">• Cancer care is part of the NCD action plan• No breakdown for cancer care; part of the health expenditure• No government institute for cancer related research and care services development• Continuous cancer and supportive care carried out within the community, mainly by untrained family caregivers• Limited collaborations between public healthcare and community organizations• Cancer services: Information support/ psycho-education, Symptom management and daily care support, Psychosocial support/ interventions, Rehabilitation, Self help groups/ peer support groups, Use of complementary and alternative therapies such as traditional Chinese medicine



Financial Needs

International Best Practices	Hong Kong
<ul style="list-style-type: none">• Tax Credits• Emergency financial assistance• Social security assistance• Disability allowance• Pharmaceutical assistance• Subsidies on accommodation and transportation• Age/ Retirement pension• Charity funds• Sickness benefit• Income support• Housing benefits• Food assistance• Concessions and health care cards• Co-payment assistance• Cancer lodges• No interest loan• Financial planning• Employment support and training	<ul style="list-style-type: none">• Tax Credit• Emergency financial assistance• Social security assistance• Disability allowance• Pharmaceutical assistance• Subsidies on transportation• Old age allowance• Charity funds



Family Support

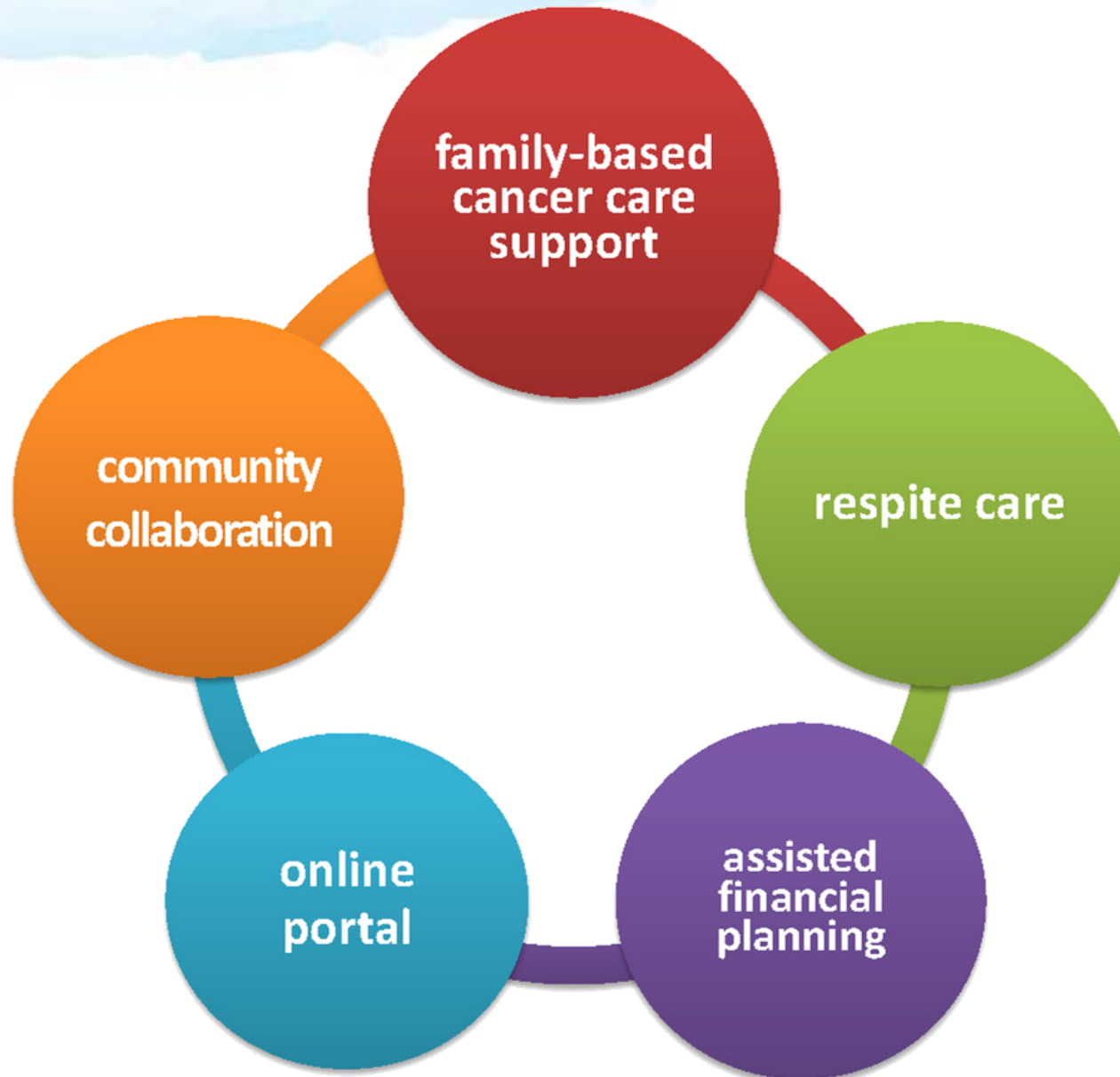
International Best Practices	Hong Kong
<ul style="list-style-type: none">• Information support/ psycho-education• Respite care and daily care support and training• Psychosocial support/ interventions• Bereavement support• Financial planning• Direct financial assistance such as carer's allowance and carer's supplement to cover costs of living and care-giving• Indirect financial assistance such as tax credit, entitled employment leave and compassionate benefits• Caregiver support programs	<ul style="list-style-type: none">• Information support/ psycho-education• Daily care support• Limited scope of psychosocial/ bereavement support• Self help groups/ peer support groups• Direct financial assistance: Social security assistance• Indirect financial assistance: tax credit



Filling the Service Gaps

Current Gaps	How The Hong Kong Anti-Cancer Society fills the Gaps
Unable to Locate Community Resources	<ul style="list-style-type: none">✓ Professional staffs act as a navigator to supply a list of available resources like cancer support groups, Government and Charity subsidies for eligible patients.✓ HKACS make its service known to patients through referral program by leveraging social workers in hospital and community centers.✓ HKACS staffs are highly committed professionals with guarantee of responsive responses to patients' specific needs.
Inconvenient cancer centers	<ul style="list-style-type: none">✓ HKACS is working with the existing community centers in New Territories, Kowloon and Hong Kong Island to host regular gatherings and sharing sessions at the patient's convenience.
Unfit Activities	<ul style="list-style-type: none">✓ HKACS has a successful "Buddy System" where recovered patients volunteer to host sharing sessions and home visits to other patients. Patient benefit tremendously from this program emotionally and also gained many practical tips that they could not get elsewhere.
Shortage of Regular Sharing Sessions	<ul style="list-style-type: none">✓ HKACS trained professional staffs make regular phone calls to show support and caring and provide practical advice targets to patients' needs. Trained volunteers pay regular home visits.
Extension of Assistance to patient's family	<ul style="list-style-type: none">✓ Patients' families also receive practical assistance from HKACS staff, eg. Staff accompanies patients' family members for ah-hoc activities like doctor visits or pick-up of children from school.

Recommendations





Recommendations



Community Collaborations

- **Community-based Professional Network** to fully utilized existing professional network, and to explore new frontiers of professional collaborations
- **Community Staff & Volunteers Training Programs for Cancer Support** to establish community-based support network for caregivers, and to encourage community participation
- **Collaborated Campaigns & Educational Programs** to fully utilized community resources in service delivery



Family Based
Cancer Care
Support



Assisted
Financial
Planning



Recommendations

- **Family Communication Sessions** to facilitate effective communications between family members in treatment- or disease-related decisions, and to empower the caregivers through making well-informed choices
- **Caregivers' Support Programs** to offer support to caregivers, to facilitate exchange of knowledge in caregiving, and to instill a sense of self-efficacy among them
- **Community Support Programs** such as campaigns to actively engage the community in the provision of assistance service to caregivers
- Policy advocate of **Caregiver Leave** to allow caregivers to take time off work



**Family-
based
Cancer Care
Support**

**Assisted
Financial
Planning**



Recommendations

Online

- **Family Caregiver Training Programs** to educate caregivers the necessary in effective care-giving to cancer patients
- **Respite Care Service** provided by trained volunteers to temporarily release caregivers from the chores of caregiving
- **Caregivers' Self Care Programs** to educate caregivers the know-hows and importance of self-care, to facilitate mutual support among them

**Respite
Care**

Family Based
Cancer Care
Support

Assisted
Financial
Planning



Recommendations

Online
Portal

- **Financial Planning Service** to assist caregivers in financial planning, and to facilitate caregiver empowerment
- **Financial Resources Navigation Service** to assist and make referral to available community resources for the caregivers
- **Employment Training & Support Scheme** to provide financial assistance to trained “full-time” family caregivers

Family Based
Cancer Care
Support

**Assisted
Financial
Planning**



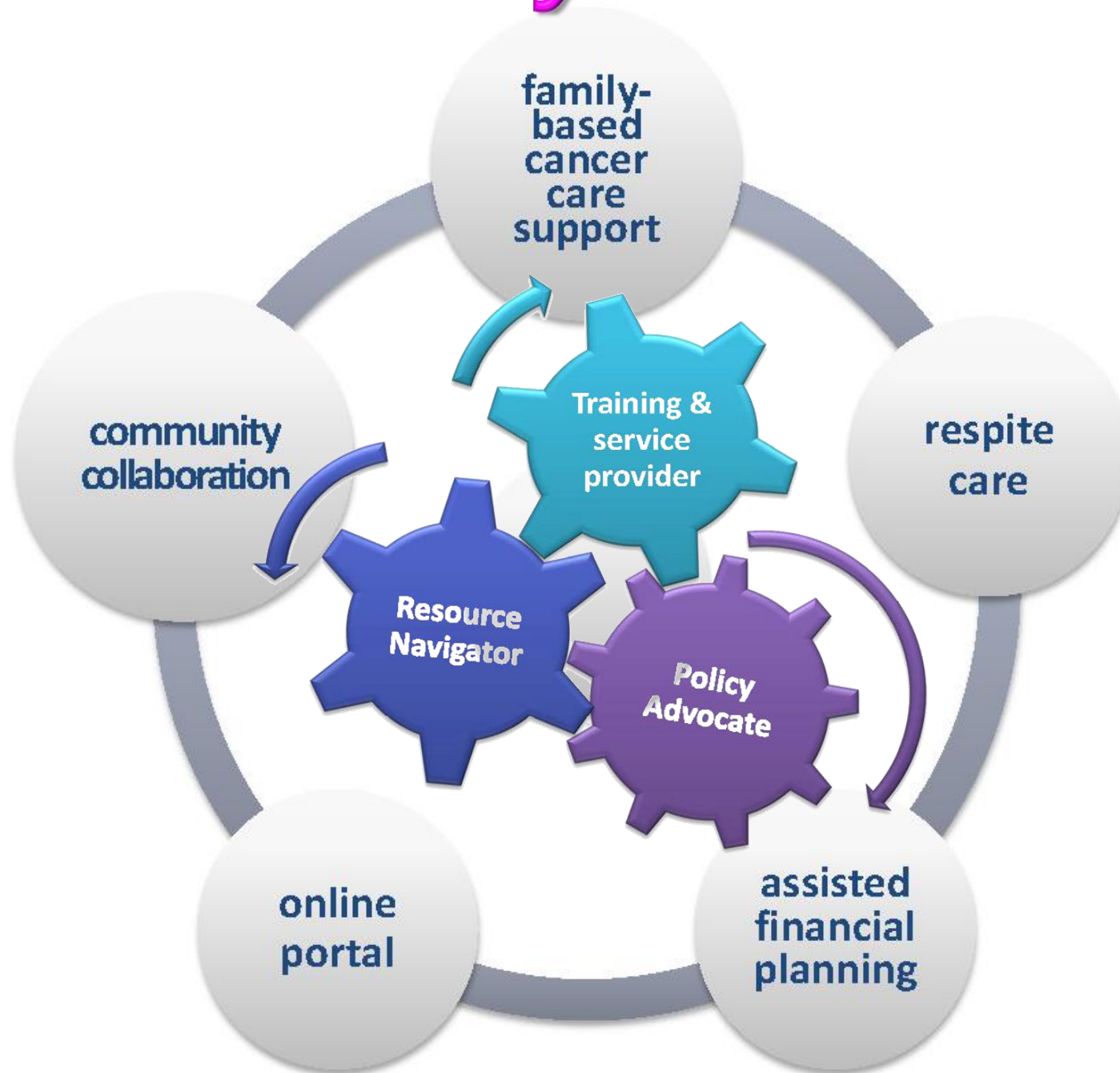
Recommendations



Online Portal

- **Self Assessment Tools** for early symptom detection and helping-seeking
- **Psycho-education materials** on practical skills, resources, and cancer-related information
- **Individualized service record**, such as an Internet-based service utilization record
- **Online Support Platform**, such as discussion forums to facilitate communications between caregivers and professionals

The Way Forward



Listen to the Voices of Cancer Patients



Thank you!



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