



Serious and Continuing Illness Policy and Practice Study (SCIPPS)

Carers & chronic illness: A policy vacuum

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Menzies Centre for Health Policy Seminar

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The University of Sydney

The **Serious and Continuing Illness Policy and Practice Study (SCIPPS)** is an NHMRC funded program conducted at The Australian National University and The University of Sydney and administered by The Menzies Centre for Health Policy



THE AUSTRALIAN NATIONAL UNIVERSITY



OVERVIEW

- SCIPPS
- Experience of family carers in SCIPPS
- Current carer policy: Commonwealth and NSW Government
- Policy problems to be overcome



SCIPPS

The Serious and Continuing Policy and Practice Study (SCIPPS) is a health policy and practice study that aims to develop policy and health system solutions to improve the management of chronic illness, including:

**Chronic obstructive pulmonary disease,
chronic heart failure and diabetes**



SCIPPS: METHODS

- Five year study
- Sydney West Area Health Service & the Australian Capital Territory
- Stage one: Qualitative study
- Target population, purposively sampled:
 - Patients: 45-85 years (n=52)
 - Family carers (n=14)
 - Health care professionals (n=66)
- In-depth interviews and focus groups
- Data analysis using qualitative content analysis





FAMILY CARERS

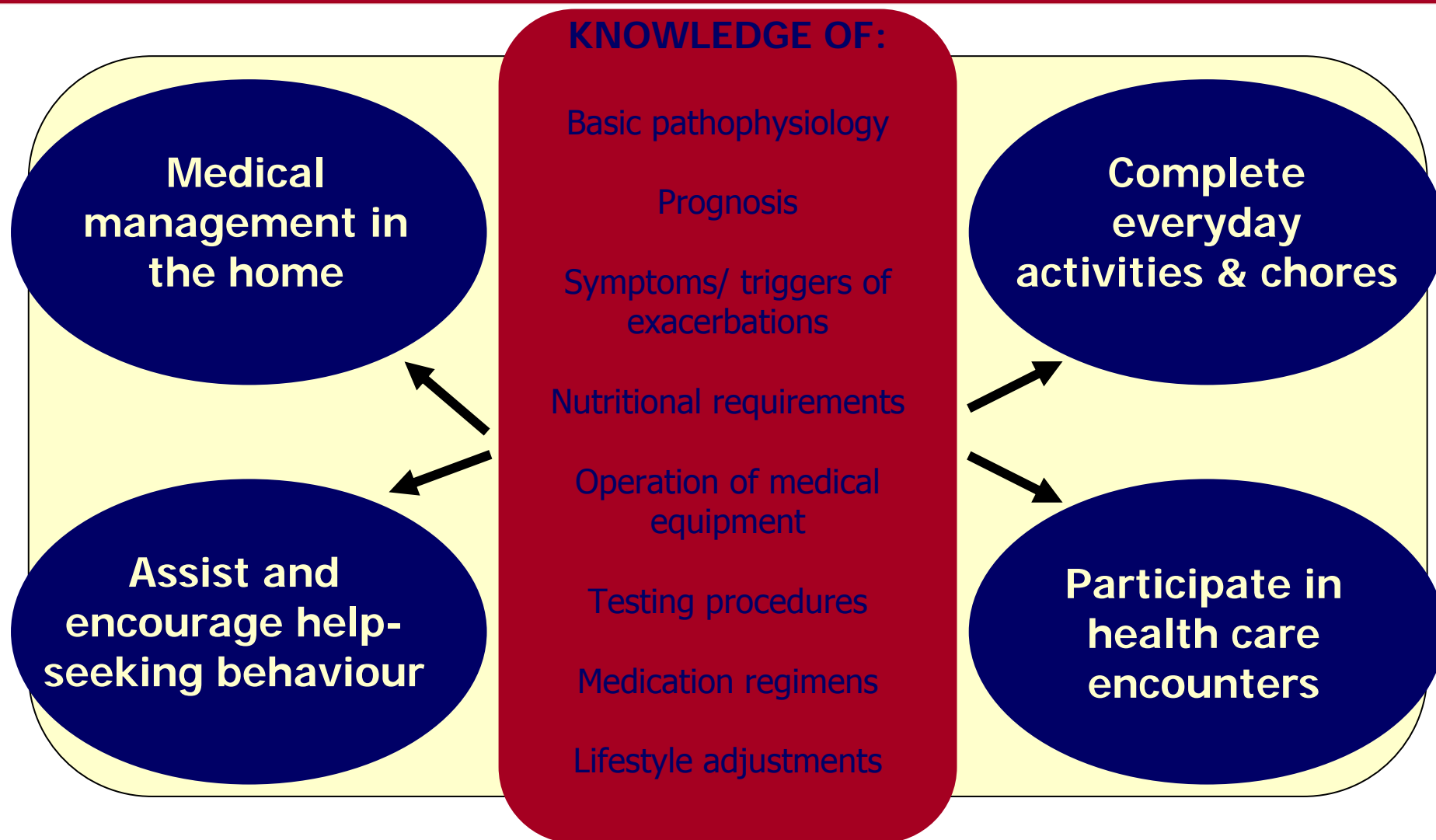
Defined as:

The most centrally involved family member or close friend providing practical and emotional assistance to a chronically ill person





FAMILY CARER ROLE





CARER EXPERIENCE

- 1. Overwhelmed by the constant, unpredictable and demanding nature of care-giving**



UNPREDICTABLE & DEMANDING

"It's more than 'fairly' demanding when you have somebody who has a chronic disease and is basically on life support as in supplementary oxygen 24/7, it's unpredictable when he will need any help, so basically I need to be available 24 hours a day, seven days a week."

60 year old female carer, COPD



CARER EXPERIENCE

1. Overwhelmed by the constant, unpredictable and demanding nature of care-giving
2. **Difficulty coping with the changing relationship with the care-recipient**



CHANGING RELATIONSHIP

"My wife [carer] is over-protective...carers really need someone to talk to them about what they can do, not to push themselves into helping you. Like I said they wrap you up in cotton wool... they need to back off sometimes, but you have to tell them and they get annoyed at you."

66 yr old male patient, CHF



CARER EXPERIENCE

1. Overwhelmed by the constant, unpredictable and demanding nature of care-giving
2. Difficulty coping with the changing relationship with the care-recipient
3. **Struggle to balance priorities between the care-recipient's needs and their own**



BALANCING PRIORITIES

"It's when I feel tired and when I feel a bit maybe shaky, it's good for me to rest a bit, but when I feel that, when I need to have a rest, something happens for example my husband ...who has a stroke, he needs to get up to go to the toilet or he needs something, and of course I have to attend to him...I forget about myself at that time."

72 year old female patient, CHF and diabetes, also a carer

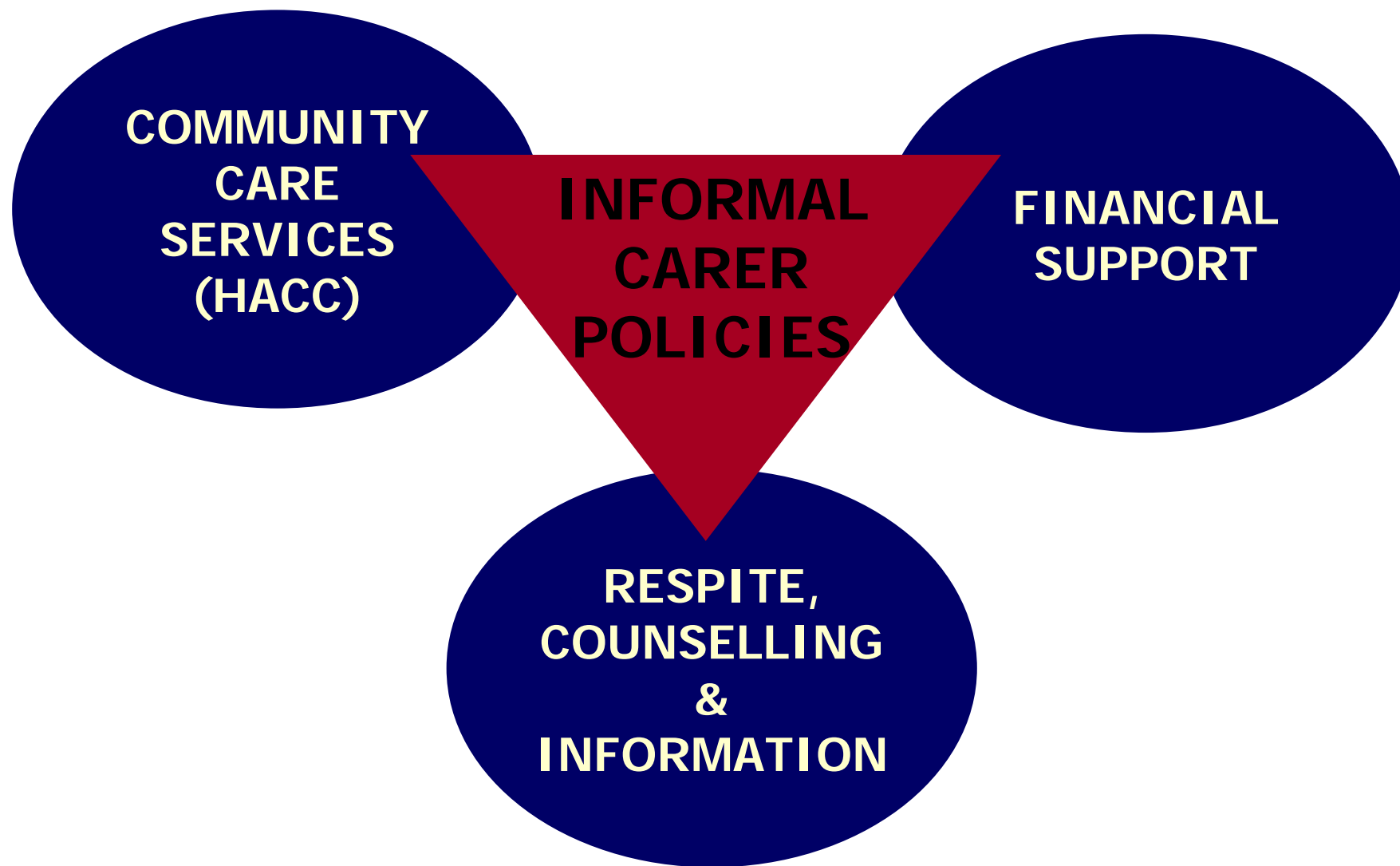


CARER EXPERIENCE

1. Overwhelmed by the constant, unpredictable and demanding nature of care-giving
2. Difficulty coping with the changing relationship with the care-recipient
3. Struggle to balance priorities between the care-recipient's needs and their own
 - Carers know about respite programs, but are unable to use this service because the care-recipient can be highly dependant on their care



COMMONWEALTH





NSW POLICY

NSW CARERS ACTION PLAN (2007-2012)

PRIORITY AREAS

1. Carers are recognised, valued and respected
2. Hidden carers are identified and supported
3. Improvement of current services
4. Carers are partners in care
5. Carers are supported to combine caring & work



What would a policy environment that effectively supported carers include?



POLICY PROBLEMS

- Carers are not supported to become 'partners in care':
 - How do we equip carers with the skills and knowledge to be partners?
 - How do we improve HCPs willingness and ability to work with carers?
- Respite care: One model of respite care does not fit all
- Carers assisting with CI management are also hidden
- Navigation of and access to available services remains problematic:
 - An audit of available services is necessary for responsible resource allocation in the future



Information & training

Practical support

Respite

Practical support

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BALANCING PRIORITIES

"...suggestions of respite ...by George going to a day centre. It's just not a practical suggestion... the portable oxygen at his level the largest tank probably lasts about two hours...also the danger of infection...the places are most likely to be places to pick up infections... and that sort of constant level of care that is needed...its pretty risky to leave anyone else in charge"

60 year old female carer, COPD