Formal and informal: can service providers and networks of care successfully collaborate in home care?

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The project

Caring at the end of life:

understanding the nature and effect of informal community care networks for people dying at home

University of Western Sydney
Bringing knowledge to life

Cancer Council NSW

CSIRO

QUT
Queensland University of Technology
Brisbane Australia

Calvary Health Care ACT
ACU
Calvary Centre for Palliative Care Research

Project partners

- ARC Linkage Research Grant 2012-2015
- Associate Professor Debbie Horsfall
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- Professor Rosemary Leonard
  CSIRO/University of Western Sydney
- Dr John Rosenberg, Research Fellow, QUT
  (formerly Director, CCPCR/ACU, Canberra)
- Cancer Council NSW
- Ms Kerrie Noonan, Research Assistant/PhD candidate,
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Key concepts

- Promotion of community capacity by palliative care services is an important strategy for improving care at home and achieving a home death

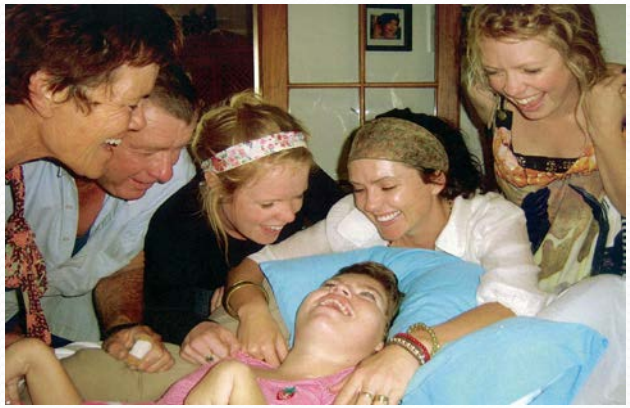
  (Hudson, 2003; Horsfall et al., 2012; Leonard et al., 2014; Masucci, Guerriere, Cheng & Coyte, 2010)

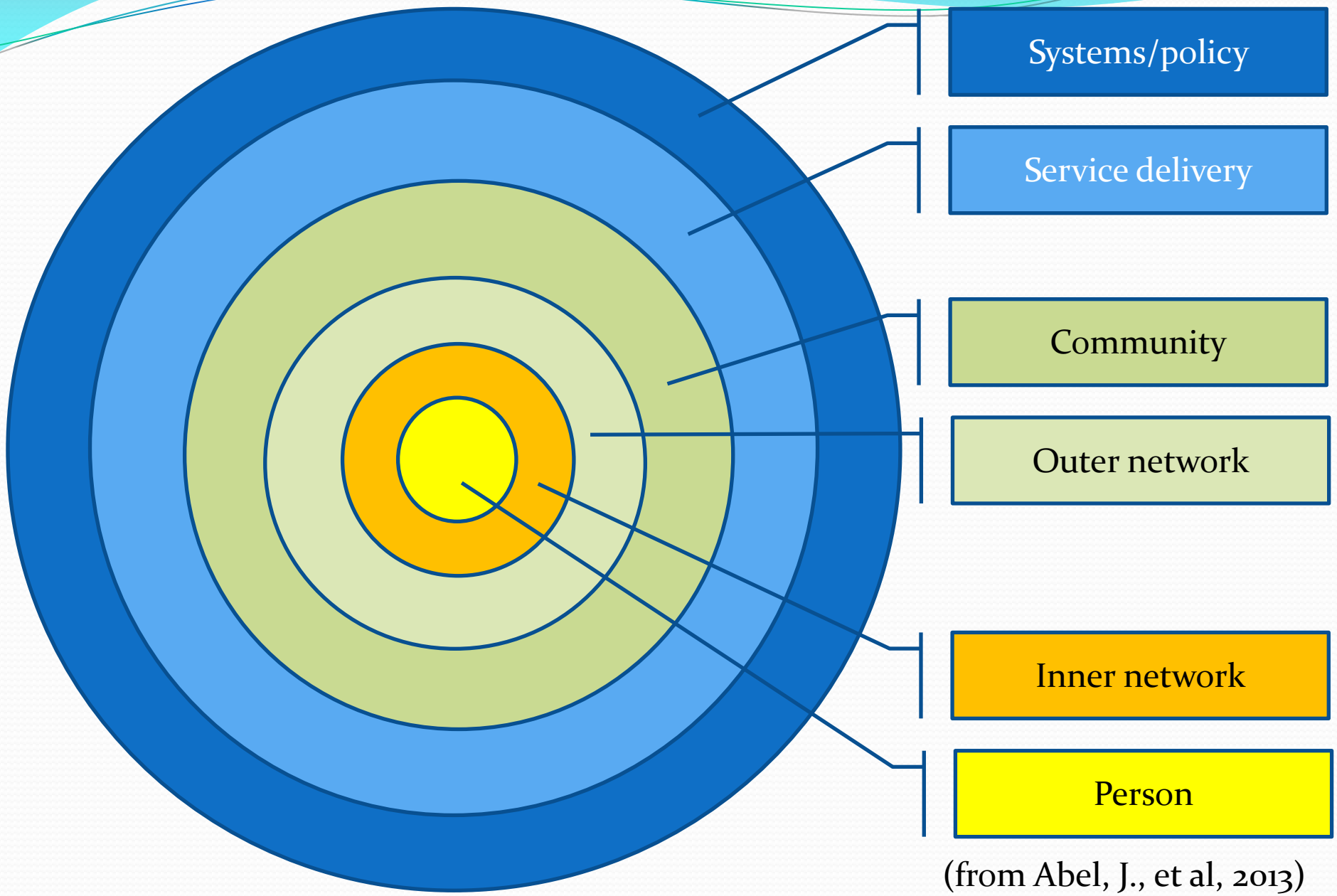
- Informal networks of care can form around a dying person and their family
- These networks themselves may have complex needs in order to provide support

  (Funk et al., 2010; Stajduhar et al., 2010)

Key definitions

- **Informal caring networks:** people identified by the carer/dying person as any person, aside from formal services, who have provided care
- **Formal caring networks:** health care professionals
- This research draws a distinction between informal caregivers, who support kin and friends, and community volunteers

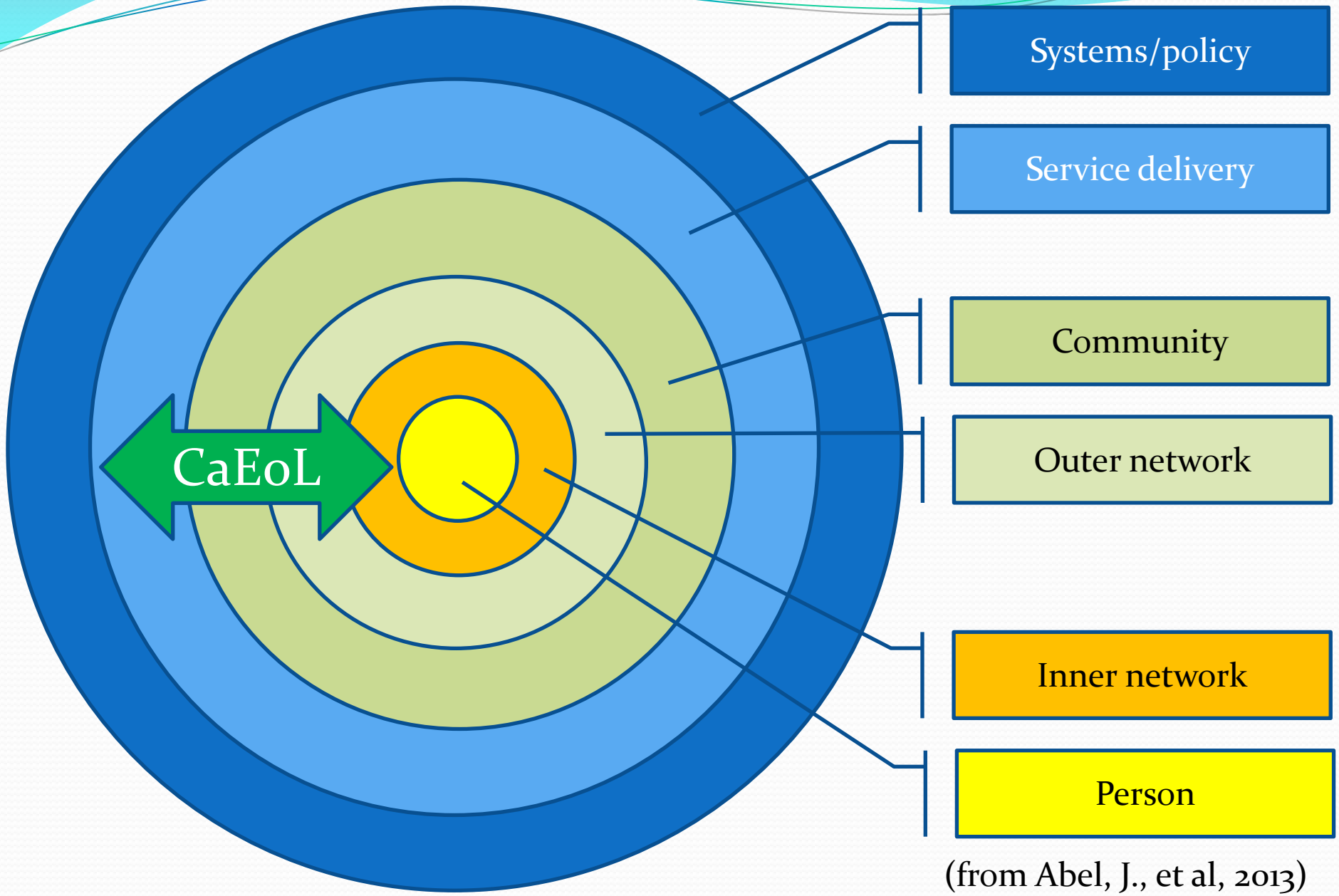




(from Abel, J., et al, 2013)

Research question and methods

- **Research question:** what is the nature of the relationship between the informal and formal carers?
- **Data collection:** interviews , focus groups, social network mapping
  - n=26 carers
  - n=84 members of informal caring networks
  - n=17 members of outer informal networks
  - n=88 representatives of service providers
- **Data analysis:** inductive process
  - thematic analysis of narrative data
  - social network analysis



(from Abel, J., et al, 2013)

Findings

- Informal networks are vital and have multiple benefits
  - to support the carer to care for someone to die at home it is essential that there is a functioning caring network and that this comprises both the formal and informal networks

"You can have support services but unless you've got that extra informal family doing those normal things with the children, doing the groceries and all those things in the house and everything like that… There are great services out there but the services just aren't enough." (FG8).

Findings

- Network respondents reported wide-ranging views and experiences of these interactions:
  - many service providers were seen to perform "above and beyond"
  - some were perceived to be highly judgmental and antagonistic towards informal caring networks
  - respondents did not routinely put formal service providers on their network maps
  - when they did, in almost all cases service providers were at the periphery of the maps indicating weaker and fewer ties to service providers than to family and friends

Findings

- Formal networks were seen to have multiple benefits
  - Assessment, providing services and equipment, help with pain and symptom management, and practical hands-on tasks, “clinical care”
  - Coordinating formal service provision such as respite care, community nursing and home care
  - Navigating the health care system

Findings

- A role in normalising death
- Building capacity of informal networks: adjusting procedures so they could be completed at home

"A lot of people are very frightened of it and really what WE can do is…provide reassurance that it is natural. Yes, there's some stuff that's going to happen that may be confronting but none of it is rocket science really and that we can provide the support that that network needs to have – to give it the skills that it needs NOW… take them through the steps of what is technically a very simple thing often but emotionally very heavy and complicated and helping them manage and support the emotional side of…" (FG7)

Findings

- Varied levels of involvement with informal networks

"We generally don't formally directly contact the informal network… if we're told that for example the church group is helping with meals and transport we don't ever talk to the church group." (FG3)

"Part of my role is to give the families a ring and see just who's on board. I'll have the family meeting and ask for all those members to come in so we play a role in bringing people together." (FG6)

Findings

- Most service providers reported informal networks as the proper context for holistic care
- Others were suspicious of the uncontrollable nature of informal networks as "members" were not screened

"Mary could be an axe murderer!"(FG8)

- Occasionally people did not have the skills to be involved or passed on incorrect information to people making the work of service providers more difficult

Findings

- Barriers to working with informal networks
  - changing nature of communities
    - two income families
    - constraints of work
    - people moving out of area to retire
    - families being dispersed
    - ageing population
    - people no longer know how to help each other

"If somebody has lived their life isolated…when it comes to the end of their life that's how they're going to die; in the way that they lived, without those supports." (FG6)

Findings

- Barriers to working with informal networks
  - complex rules and regulations
  - risk management
  - privacy
  - confidentiality
  - lack of home visiting
  - lack of 24 hour support
- relationships weakened or disrupted by poor or inappropriate services, or insensitivity of service providers
- conflict between the personal approach of the informal network and the professional approach of the formal service providers

Findings

- Even good relationships during the caring period usually ended abruptly when the person died which could leave carers feeling deserted or struggling with daily tasks because the services were only provided for the dying person
- No discussion of the benefit of the formal networks to the community

"Quite often it's just friends. There are a few people who seem to be really aware of what's happening in the community as far as sickness and illness goes." (FG8)

Conclusions

- A complementary, but separate, relationship between formal and informal networks
  - formal service providers can identify capacity of the existing informal network
  - develop the network by providing information, education/training, sharing stories, and reassuring the networks in their roles and tasks
  - usually, but not always, from a 'service provider as expert' position rather than a community development position
- However formal services currently appear to play a minimal role in mobilising informal caring networks

Conclusion

- Good outcomes for the dying person, their carer and the network members were achieved when formal services were well integrated within the informal caring network
- Integrating formal services within the caring network – not the other way around – counters the paternalism inherent in many models of health care
- Recognising the primacy of the caring network as a whole, and facilitated by service providers, strengthens relationships between formal service providers and informal networks

Final words

"I guess the best way of developing the informal networks in communities is … the community actually building up the social capital so that there are things to go to, ways of meeting people, ways of connecting people. The better that people are connected in communities, the more informal networks you're going to have which are then going to be useful when there's a palliative issue. So it actually starts a lot earlier…" (FG7)