Developing Palliative Care in Rural Communities

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ICE RURAL PALLIATIVE CARE

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Research Objectives

- Validate a 4 phase conceptual model for developing rural palliative care programs
- Implement and evaluate the model as a theory of change to develop rural palliative care programs

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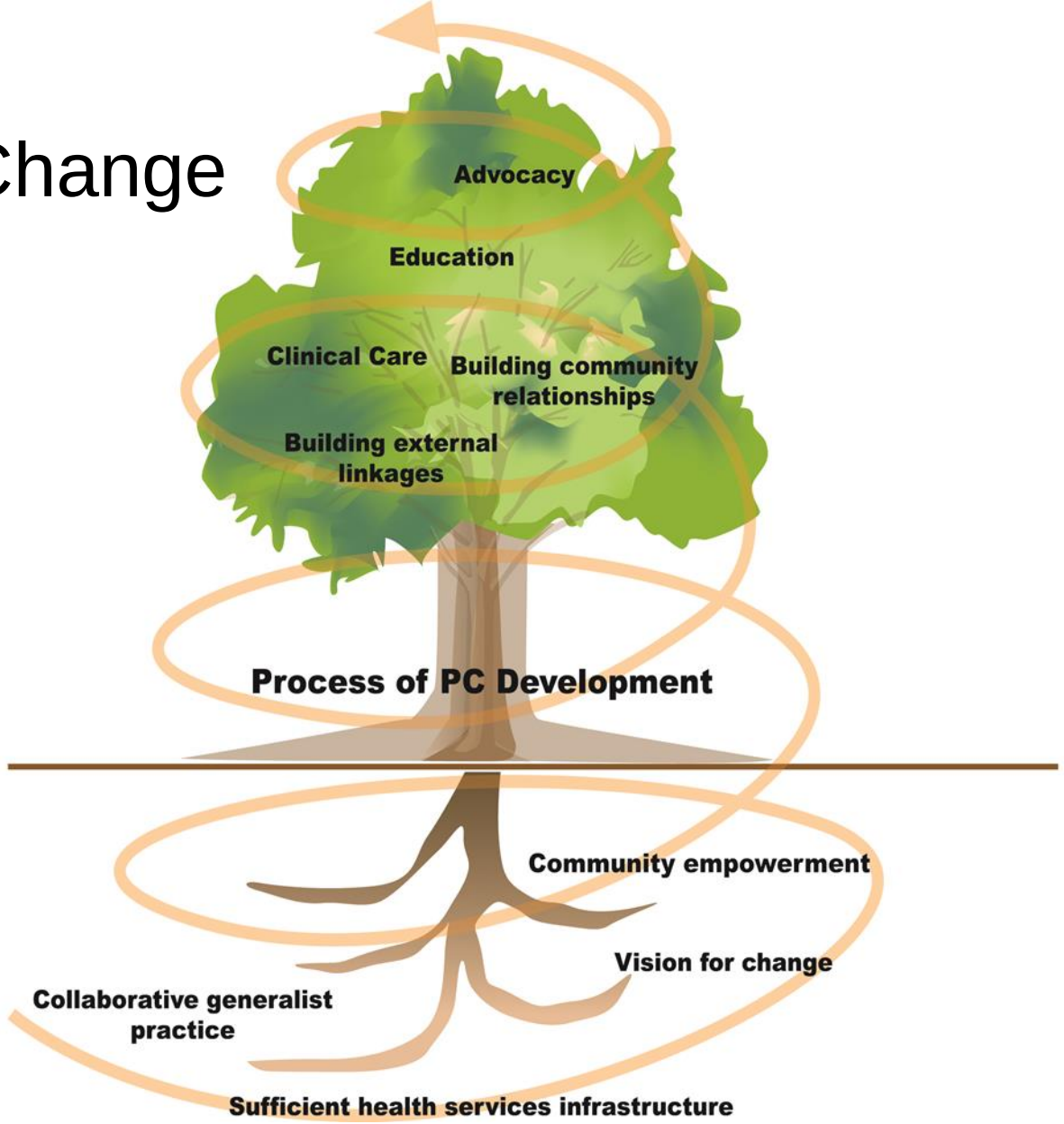
The Theory of Change

Rural
Palliative
Care Program

Antecedent
Community
conditions



PHASE 1

HAVING ANTECEDENT COMMUNITY CONDITIONS

- Having sufficient local health infrastructure;
- Having a collaborative generalist practice;
- Sharing a vision of change;
- Having a sense of local empowerment.

- *Keys to success* are:
  - Working in a small community,
  - Working together, and
  - Being community focused.

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We built on what exists…

We didn't create a lot of new positions to do this…everybody was already there….we did it with what we had….we were proud of that.

One key [is] to first use the local things, whatever they have: their local wisdom, their local this, and then add to it instead of introducing something that's completely new.

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PHASE 2

EXPERIENCING A CATALYST FOR CHANGE

A person or event disrupts the community's status quo, e.g. a local champion, new policy or education.

Provides momentum and motivation to create change.

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Examples of catalysts..

- Palliative care education
- A “bad death”
- A “local champion”
- Project funding/development initiative
- MOH Policy change-end of life care strategy
- Action Research

- Cannot be *“imposed”* from outside

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Vision for Change

- *So, anyway, to make a long story short, the lady died in hospital several months after we were all introduced to her and she died a miserable death, … we all felt like we really missed the boat with her. She had so many end of life issues that we couldn't even begin to deal with. We didn't know how to, we didn't have the resources and we really felt like she dropped through the cracks and we just dumped her really. We felt awful about it and we didn't ever want it to happen again!*

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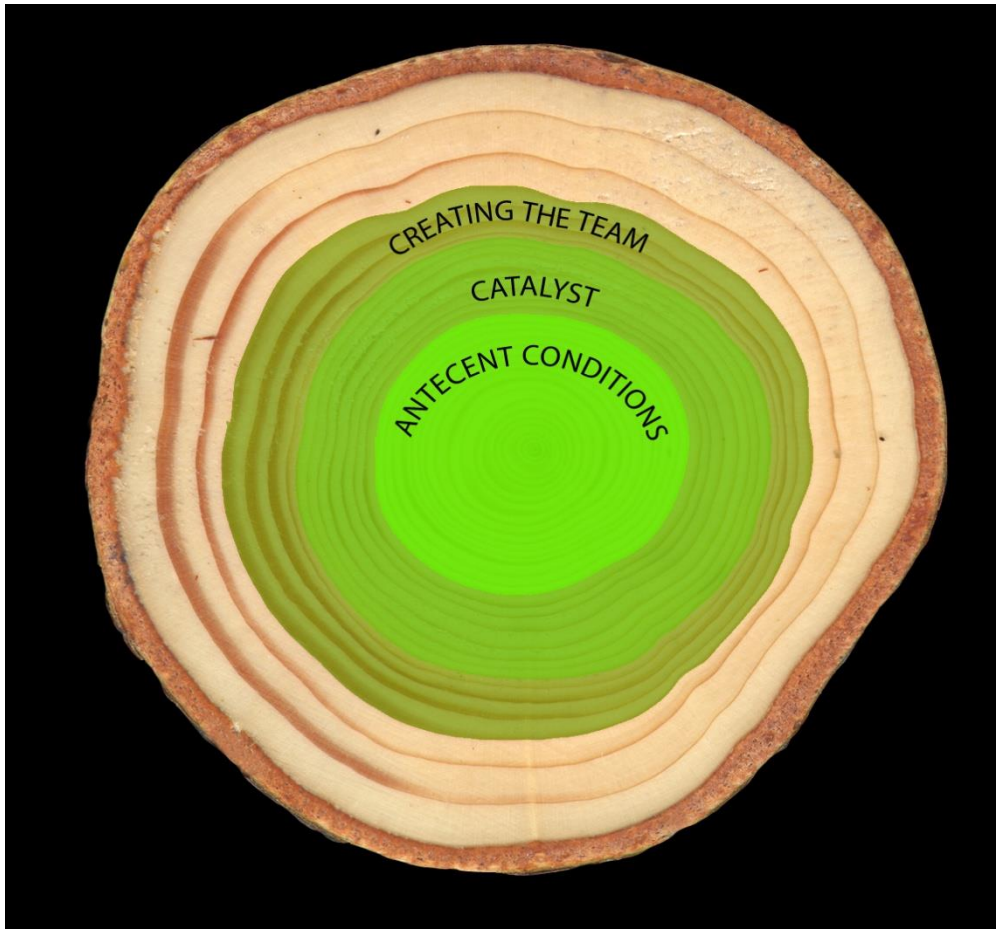
PHASE 3

CREATING THE LOCAL TEAM



- Requires having dedicated providers and getting the right people involved.
- *Keys to success* are:
  - working together,
  - dedication, and
  - physicians' support

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Creating the team…

- *The people who started on the team were very committed to the whole idea of palliative care, recognized that we could improve the services that we were providing if we worked together. And I'm not suggesting that palliative care was not being provided because of course it was in the hospital, in the community. Just everybody was doing their own thing and nobody was coming together to discuss issues or to have each other for support … {Mm hmm}, [or] organize some educational inservicing.*

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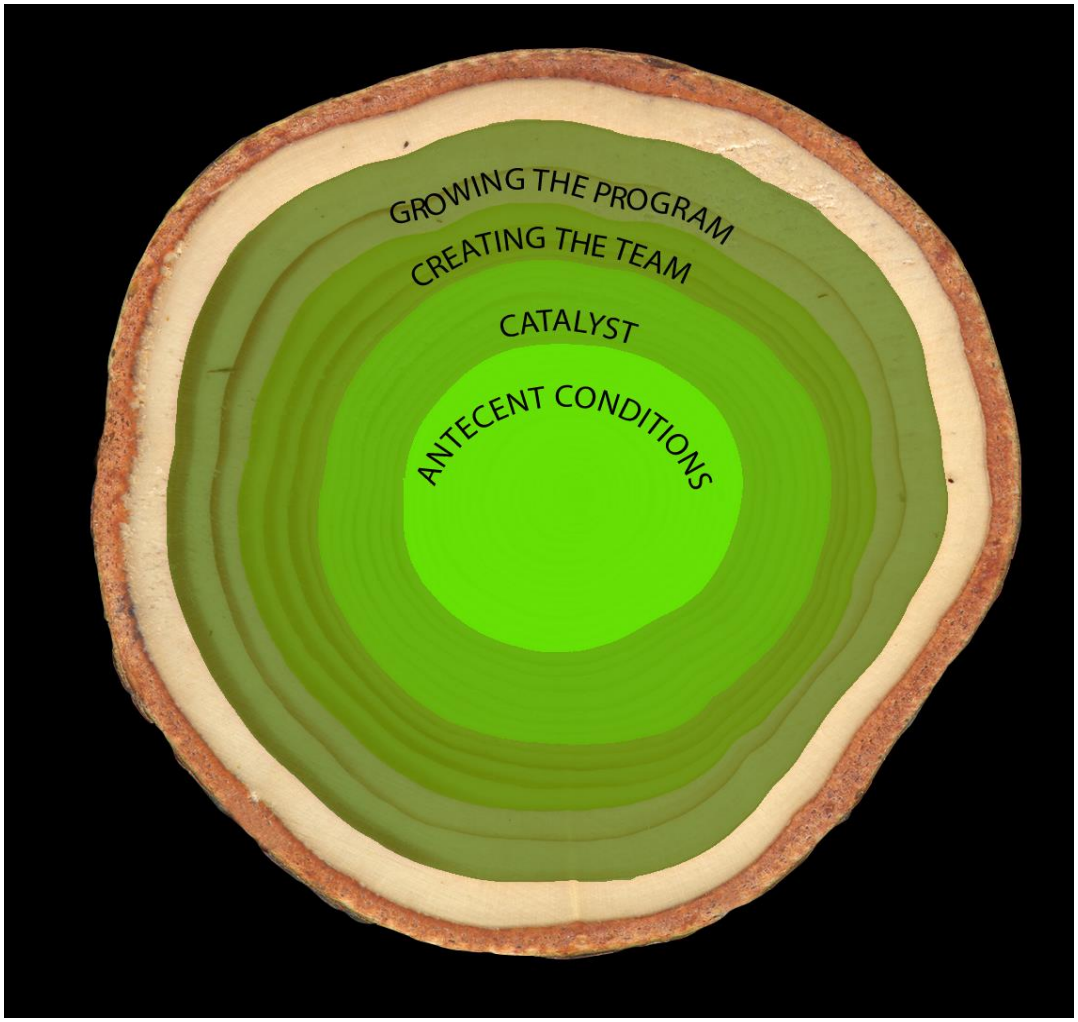
Growing the Program



The team continues to build, but now extends into the community to deliver palliative care.

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PHASE 4

GROWING THE PROGRAM

- Involves strengthening the team,
- Engaging the community and
- Sustaining palliative care.

- *Keys to success* are:
  - Remaining community-focused,
  - Educating community providers,
  - Teamwork,
  - Having local leadership and
  - Feeling pride in accomplishments.

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Doing it with what we had

- *We try to do the best we can with our clients, with what we have. And I think that a great asset to us is because we have such good communication and a great team of people work with in the community, who are very interested in caring.*

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Strengthening the team

- Developing members' expertise
- Sharing knowledge and skills
- Creating linkages outside the community
- Learning-by-doing (taking risks)
- Developing members self-confidence

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Engaging the community

- Changing clinical practices
  - Developing/implementing tools for care (e.g. in home chart, ESAS, PPS)
  - Care planning
  - Family education & support
- Educating and supporting community providers
- Building community relationships to improve service delivery

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Sustaining palliative care

- Volunteering time
- Getting palliative care staff and resources
- Developing policy and procedures

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Challenges: Growing the program

- Insufficient resources
- Organization and bureaucracy in the health care system
- Lack of understanding/resistance to palliative care
- Nature of the rural/LTC environment

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Research Outcomes

- Model is conceptually validated to explain and predict the development of local palliative care programs in rural communities.
  - Applicable nationally and potentially internationally
- Model is applicable to guide the development of local palliative care programs as a “theory of change”
  - Tool kit developed and evaluated
  - The development process, structure and dynamics of rural PC teams now understood.

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Outcomes cont'd

- Model is applicable as a guide for regional development to identify what resources are needed where and when.
  - Applicable to planning and service development by LHIN, health authorities, EOLC Networks etc.

- Model is applicable to evaluate and track the evolution of regional teams.
  - Applicable to policy and decision makers who need to provide resources

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