

Identifying, representing and utilising patients' care networks: What do health professionals learn and what can we learn from their learning?

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research



Department of General Practice
& Rural Health
*Te Tari Hauora o te Marea me te
Hauora o te Huka Ahuwhenua*

Care Maps study

- Aim: to explore how useful it is to include care maps as part of the clinical record, as a tool for coordinating and integrating local healthcare delivery for patients with complex, long-term conditions.
- 12 patients with multiple LTC – average age 74 (39-95)
- Recruited from Mornington Health Centre, Amity Health Centre, Aurora Health Centre, RDNS
- Interview, validate map, update map monthly, attend primary care appointments
- Evaluation interviews – 12 patients, 9 family members, 2 neighbours, 5 core health professionals and many others answered questions via email/phone.

MEDICAL

ALLIED

[Patient's name] is a musical man. His faith is important to him. He enjoys meeting and talking with people, having been given back his life after depression. He has cared for many people in his life. He would like people to listen to him, ask if they don't understand or agree. He wants to know before plans are made. Mid-term goal: get pain to manageable level so I can do things.

Wives,
child who
passed
away

Dr

Dr

Past

Advanced Directive

Key
Family and friends
Hospital based care
Primary based care
Allied health
Community/activity
Service
Excluded
Missing from care
Past care participant
* Enduring Power of Attorney

Psychologist
District Nurses

Nurse

Access carers

Bay Audiology

Ear Health

Steady as you go

Cleaner

GP

Patient's Name

Reverend

Church

Social club

Choir

Bowls

Lawyer*

Volunteer

Treatment for Arthritis; Faith & Learning course

Cousin & Wife

Friend

Friend

Friend

Friends

Neighbours

Friend

INFORMAL

SOCIAL

MEDICAL

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ALLIED

Wives,
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Dr

Name: GP
Role: GP, pills, check up, wound care
Value: Looks after your general health
Location: Health Centre
Contact: Phone number
Frequency: 3 monthly
Other: would like help with Arthritis. Has a copy of my advanced directive

Access
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Health professionals learned:

- increased understanding of patients' support networks
- synthesising information
- identifying gaps
- patients' perceptions of health professionals

I'm sort of familiar with his inner circle stuff... I was actually quite surprised how many different people and things were involved with one person (GP)

What really matters to patients

- I particularly picked up on [Patient's] family meals that were important to him and it was very interesting talking to him about that. The way that had developed over the years since his dad died. (GP)
- That they did have lives outside of [the practice]. Despite their impairments and disabilities they, all of them do things... However hard, physically hard life is they still make a go of it. (GP)

Therapeutic value

- it alerted me to the fact that she seemed to be withdrawing socially, and that I'm not sure I would necessarily have picked up on that without the map. I think in a way I was quite surprised to find all the things she had been doing, perhaps more than I would have expected, but also surprised to find, or perturbed to realise that she was withdrawing, or seemed to be heading down that track... Without the map I wouldn't have been aware of the issue probably and I wouldn't have had as easy an in to get to talk about it... it was also a tool to address that problem (GP)

Therapeutic value

- We may feel that I know my patient much, much better. Does that make a difference though? Should that be something we should aspire to? Or is it necessarily the doctor that should know the patient's situation that well?... We do over the years get a knowledge of a lot of our patient's background and so forth, but often, if you don't ask the question, you don't get the answer... We don't actively set out to construct this full picture of people's lives, but does it make a difference knowing those things? Sure... It gives us a three dimensional picture of who the person is. Does it affect the quality of medical care? I don't know. Is it the best use of our time? (GP)

Reflecting on practice

- I think the other good thing for me, from this point of view, is that very often when you're dealing with complex patients, you feel that you're it. You're the social worker, the letter writer, the solver of problems, arbitrator to the family disputes. It was really nice that to see that no, I'm just one of many cogs in this big wheel. Actually able to say to the patient, well you do have other people you can use during this. You know, you do have other staff and that. I'll write the letter but my role is to be a doctor. It's not my job to be everything (GP)

Utilising patients' social networks

- Social networks play an important part in the LTC management
- Synthesise the big picture
- Conversation prompt about how their care is working
- Insight into patient's view of who is important/peripherally involved
- Identify gaps and unmet needs = find solutions from within network
- Social context to inform decision-making
- Remind patient of who else is available for support
- Refer to others by name
- A fast informative summary for new carers

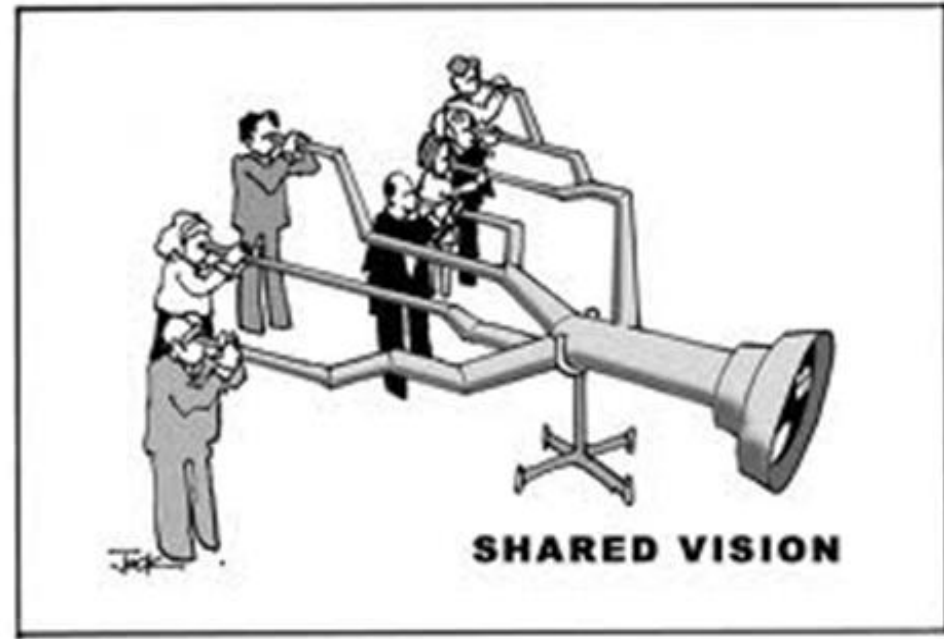
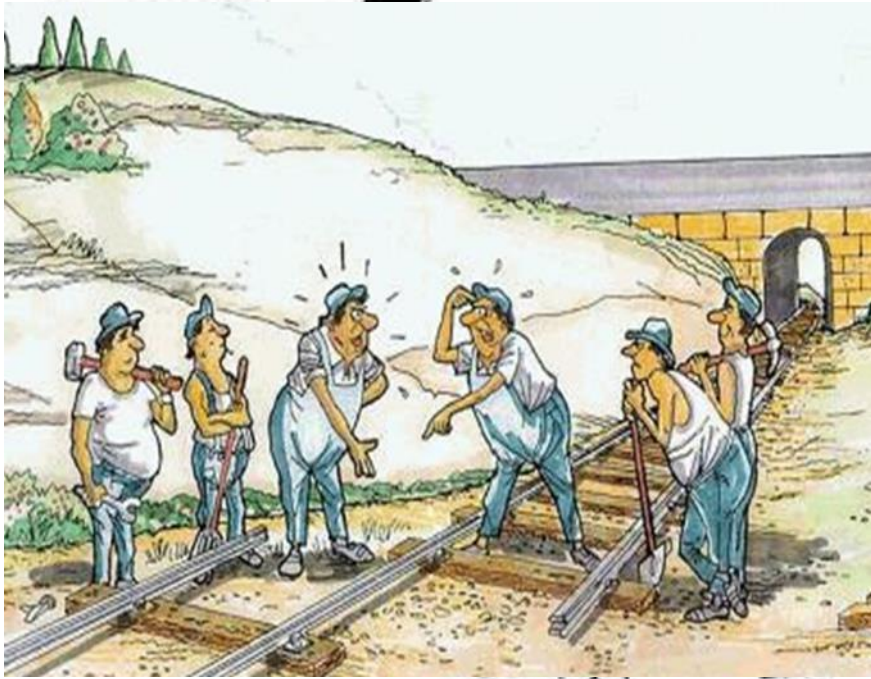
What did patients say?

- Makes me feel important. Look at that, in charge of all of that... [It tells people] that I do need help. I'm getting older and older (Patient)
- it would give [my health professionals] the opportunity to see who was about (Patient)
- If I wasn't able to communicate well to them at that stage or [Wife] aren't around and I didn't have my file notes or my hospital. People who are in that sort of situation, it gives the health professional another voice to hear about me. (Patient)
- It's just reassuring every now and then to get it out. To go through the map and read about the people that matter to me and it's reassuring. I feel cared for and loved... It just gives me a feeling of warmth when I look at it and read it. (Patient)



Thank You!

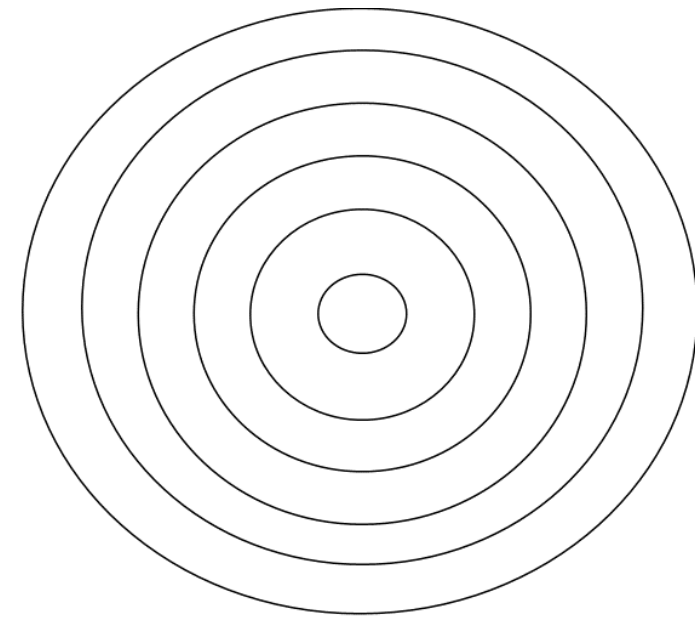
Questions?



Communities of Clinical Practice

- Communities of clinical practice
 - each patient receives care formally from health professionals and other agencies and informally from family/whānau, friends, community.
 - All of these people share a common purpose of supporting that patient's well-being
- Patient's vision of care
 - what the patient wants and needs for their life, their aspirations and desired outcomes. Their values and wishes help to determine what care is required and what care is acceptable to the patient.
- Team?

Making maps



- Which patients need maps?
- Interview – explain goal of session, chat about their CoCP, draw on paper
- PowerPoint template
- Check with patient its accurate
- Ask who they think should have a copy
- Check regularly for changes

Discussion: How might it be used to support self-management?

- How important is it to know about the patient's network of care?
- Who should know about who these people are?
- What information about a patient's care network is useful?
- Where should this information be stored and who should keep it up to date?
- Will health professionals use this information if it's available to them?

How does this fit with self-management?

- Social networks play an important part in the LTC management
- Health the “ability to adapt and self-manage” (Huber et al., 2011)
- Self-management for some patients means working with many professionals, services and agencies
- “very often when you're dealing with complex patients, you feel that you're it. You're the social worker, the letter writer, the solver of problems, arbitrator to the family disputes. It was really nice that to see that no, I'm just one of many cogs in this big wheel. Actually able to say to the patient, well you do have other people you can use during this... I'll write the letter but my role is to be a doctor. It's not my job to be everything” (GP)

Why we need Care Maps

- “I’m vaguely aware that there is family in the background, the niece you’ve got listed there but I wouldn’t be aware of the specifics like how often they have contact. I’m aware that she’s got some sort of home help and that that lady helps her with her medication. But it’s sort of a vague, vague impression... I wouldn’t be able to say for certain” GP
- “when things go wrong in the hospital and health system it’s because nobody’s got all the information. But, it’s not a very sustainable system having one person with all that knowledge in their head” LTC Nurse