

What Can Cancer Care Learn from the Chronic Condition Management Field?

Associate Professor Sharon Lawn

Flinders University, Adelaide, SA

What we know:

- An invisible population on a lot of medications with a lot of complications of cancer & its treatment
- Current approaches to care not economically sustainable given rising rates of survivorship.
- Many are 'lost in translation' between specialist care and PHC (Hewitt et al, 2005).
- Little is known about how people affected by cancer manage to live with persistent problems once primary treatment is complete, & how they can be supported to do this.

What we know:

- Dealing with others' expectations that life should be 'back to normal'
- Largely regarded and treated within an acute illness framework
- Realisation that there are chronic changes associated with cancer = new challenges
- Disrupted identities into new and changed identities (Bury, 1982, Frankl)
- Supporting self-management through partnership = reverses the focus on telling patients what they 'should do' to one where the patient is supported in addressing their own agenda.

Self-Management of Chronic Conditions

- Optimal health outcomes achieved by evidence based medical management & self-management i.e. [a partnership](#)
 - Self-management is what the patient does
 - Self-management support is what the health professional provides
- A collaborative partnership between patients & HCPs (Von Korff et al, 1997).
- Integral in re-establishing personal ownership.
- People with high self-efficacy are more likely to engage in self-management behaviours (Regan-Smith et al, 2006).

Definition of Self-Management

The Centre for Advancement in Health (1996) proposed the following definition:

“Involves [the person with the chronic disease] engaging in activities that protect and promote health, monitoring and managing of symptoms and signs of illness, managing the impacts of illness on functioning, emotions and interpersonal relationships and adhering to treatment regimes.”

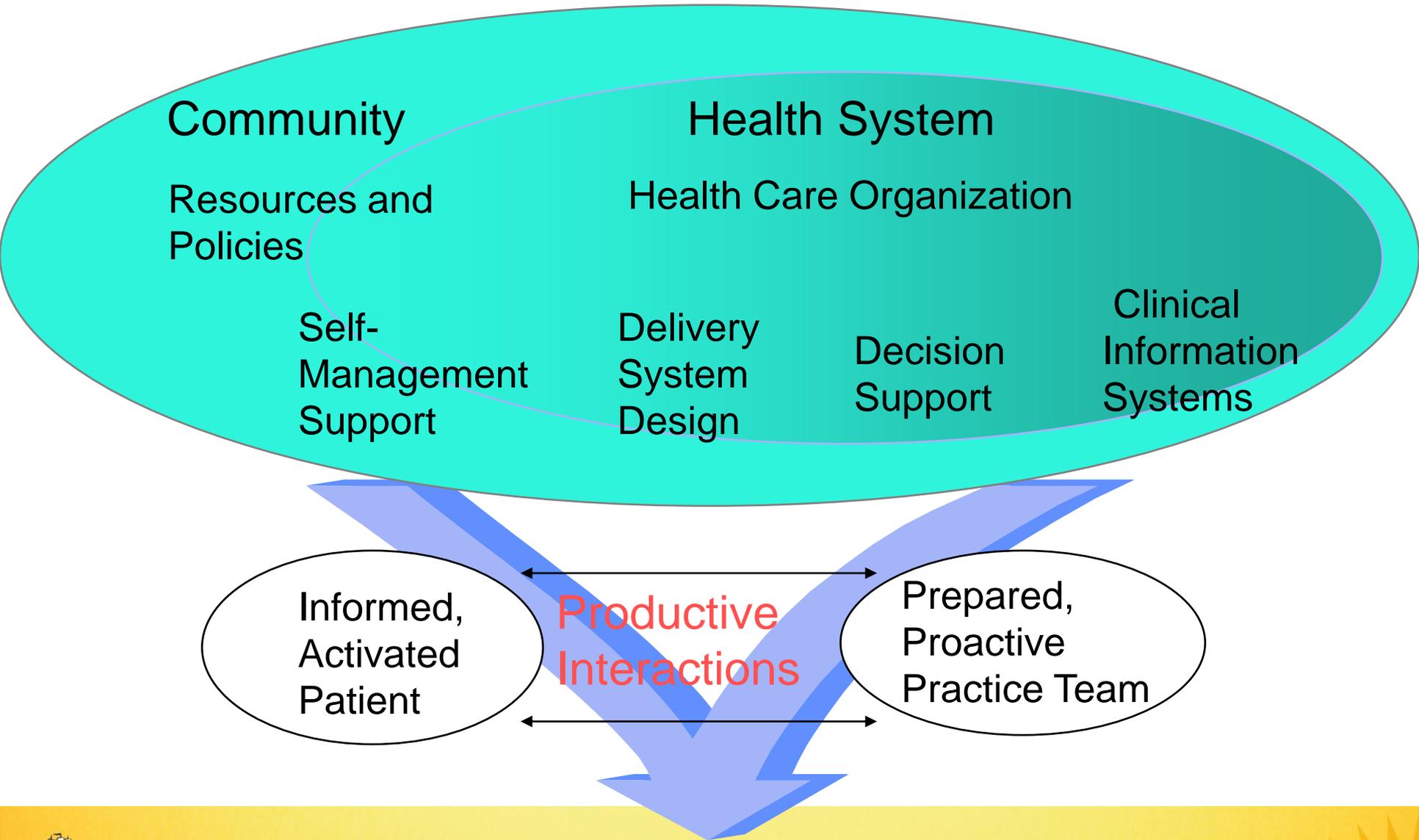
Seven Principles of Self-Management

1. **K**now your condition
2. Have active **I**nvolvement in decision making with the GP or health workers
3. Follow the **C**are plan that is agreed upon with the GP and other health professional
4. **M**onitor symptoms associated with the condition(s) and **R**espond to, manage and cope with the symptoms.

Seven Principles of Self-Management

5. Manage the physical, emotional and social **I**mpact of the condition(s) on your life.
6. Live a healthy **L**ifestyle
7. Have confidence, access and the ability to use **S**upport services

Chronic Care Model

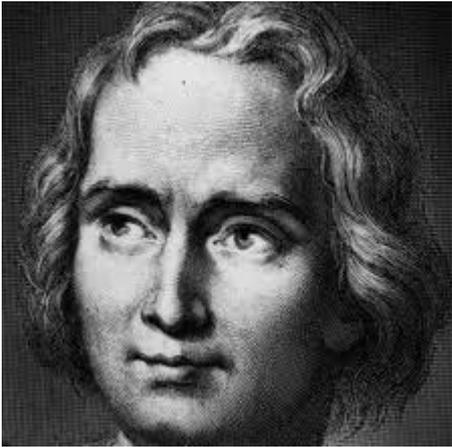


The Big 'C' or the little 'cc'

Research in the RTW area prompts a number of questions:

- Is the shock of cancer diagnosis different to other chronic conditions? Why? Why not?
- Manager's and work colleagues' view? –expectations of the person's return to the 'old' self? Assumption of care and cure within an acute perspective?
- Managers' & colleagues' fear and prior experience of cancer affects their workplace interactions with the cancer survivor? Unsure of boundaries and maintain distance to avoid becoming emotionally burdened?

- Why is it different for cancer compared with other chronic conditions?
- Why is this more so in Australia than in the US and UK?
- Will the shift to a CCSM view of cancer mean that an increasing number cancer survivors will eventually RTW?



Cancer Survivorship & CCSM

- Cancer as a chronic condition places new demands on patient and families to manage their own care, and it challenges old paradigms that oncology's work is done after treatment (McCorkle et al, 2011).
- Care planning should focus on evaluating patients' needs, clarifying support pathways, increasing the profile and involvement of community services and organisations, and supporting patients and families to develop effective self-management skills (Harvey et al, 2012).
- Targeting need and promoting motivation to participate and maintain adherence - the most important factors to emerge in ensuring positive health outcomes (Cockle-Hearne & Faithfull, 2010).

What does follow-up care look like?

Canadian study of 330 PCPs' views on providing follow-up to cancer survivors:

- Most routine follow-up care performed by medical, radiation and/or surgical oncologists - ie. Specialist care even when well –acute care model?
- PCPs follow-up if they are given:
 - a letter,
 - guidelines,
 - expedited re-referral route if needed
 - expedited access to investigations for suspected recurrence
- 72% of physicians perceived that patients expected to receive specialist follow-up. This suggests that patient perceptions also need to shift towards CCSM support delivered in primary care settings
- Finding confirmed by other studies with physicians and patients.

Cancer Survivorship CCSM Care Plans?

Grunfeld et al. (2011) evaluation of survivorship care plans (SCPs) for 408 breast cancer survivors.

Each received a discharge visit with oncologist and discharge letter sent to PCP consistent with usual care. SCP included:

- a personalised treatment summary
- a patient version of the Canadian national follow-up guidelines
- a summary table of the guideline to act as a reminder system
- a resource kit tailored to the patients' needs on available supportive resources
- Compiled in a binder and reviewed with the patient in a 30 minute education session

What needs to happen?

- Shift to SM needs to begin at point of diagnosis with a collaborative, empowering & interactive relationship between patient & HCP
- Shift in perception of clinician from expert to enabler
- Shift in perception of patients from passive recipients to active participants in their care
- Support to put knowledge into practice ie. apply it to their situation [// learning to apply to new problems as they arise, KICMRILS]
- SM is more than just knowledge acquisition
- Self-efficacy/confidence to SM [the most significant thing affected after cancer diagnosis, treatment & survivorship]

(Davies & Batehup, 2010)

Capabilities for Effective CCSM Support

| Person-Centred Skills | Behaviour Change Skills | Organisational/Systems Skills |
|--|--|---|
| 1. Health promotion approaches | 9. Have knowledge of models of health behaviour change | 14. Working in multidisciplinary teams / Inter-professional learning and practice |
| 2. Assessment of health risk factors | 10. Motivational Interviewing | 15. Information, assessment and communication management systems |
| 3. Communication skills | 11. Collaborative problem definition | 16. Organisational change techniques |
| 4. Assessment of self management capacity (understanding strengths and barriers) | 12. Goal setting and goal achievement | 17. Evidence based knowledge |
| 5. Collaborative care planning | 13. Structured problem solving and action planning | 18. Conducting practice based research/ quality improvement framework |
| 6. Use of peer support | | 19. Awareness of community resources |
| 7. Cultural awareness | | |
| 8. Psychosocial assessment and support skills | | |

But how do you put all of this together in practice?

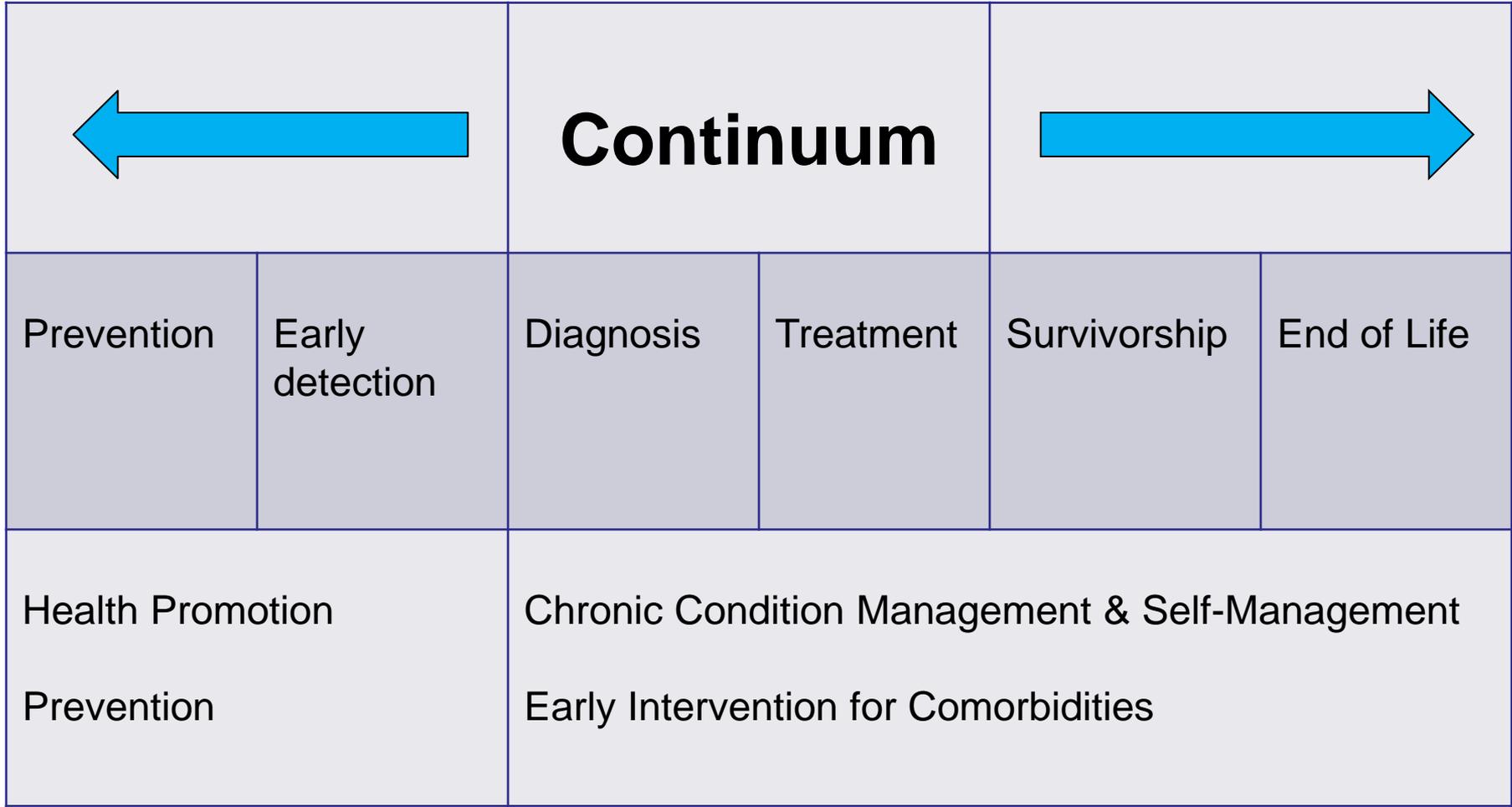
The Flinders Program:

1. The person self-rates what they currently know and do
2. Have a conversation about it (What they do well, not so well and where barriers exist)
3. Identify the main problem (from their perspective) and a SMART goal (something they wish to achieve to address the problem)
4. Organise the issues on a SM Care Plan which is shared
(Issues, Aims, Steps to Get There, Who's Responsible, When to Follow-up)

<http://www.flinders.edu.au/medicine/sites/fhbhru/>

Feasibility & acceptability of these approaches

- Recent collaborations at Flinders University between chronic condition and cancer care researchers.
- Lifestyle interventions (diet and exercise), complementary therapies, and rehabilitation, focused on person-centred, motivational and goal-focused support.



Is 'Survivorship' at odds with 'CCSM'?

- MH one of the few areas where 'survivorship' term is sometimes still used.
- Past examples of diseases, now treatable, that people commonly died from.
- When we stop calling it survivorship, then we will know it is truly a chronic condition.



References:

- > Berg C, Hayashi RJ. (2013) Participation and self-management strategies of youth adult childhood cancer survivors. *Occupation, Participation and Health* 2013 - Volume 33 · Issue 1: 21-30. DOI: 10.3928/15394492-20120607-01
- > Bury M. (1982) Chronic illness as biographical disruption. *Sociol Health Illn* 4(2),167–182.
- > Charmaz K. (1983) Loss of self: a fundamental form of suffering in the chronically ill. *Sociol Health Illn* 5(2),168–195.
- > Cockle-Hearne, J and Faithfull, S (2010) Self-management for men surviving prostate cancer: a review of behavioural and psychosocial interventions to understand what strategies can work, for whom and in what circumstances *PSYCHO-ONCOLOGY*, 19 (9). 909 - 922.
- > Davies NJ, Batehup L. (2010) Self-management support for cancer survivors: guidance for developing interventions. *Macmillan Cancer Support: Department of Health, UK. National Cancer Survivorship Initiative Supported Self-Management Workstream.*
- > Del Giudice ME, Grunfeld e, Harvey BJ, Piliotis E, Verma S. (2009) Primary care physicians' views of routine follow-up care of cancer patients. *J Clin Oncol* 27(20), 3338-3345.
- > Foster C, Fenlon D. (2011) Recovery and self-management support following primary cancer treatment. *Br J Cancer* 105(S1), S21–S28. doi: 10.1038/bjc.2011.419
- > Grunfeld E, Julian JA, Pond G, et al. (2011) Evaluating survivorship care plans: results of a randomized, clinical trial of patients with breast cancer. *J Clin Oncol* 29(36), 4755-4762.

- > Harley C, Pini S, Bartlett YK, Velikova G. (2012) Defining chronic cancer: patient experiences and self-management needs. *BMJ Support Palliat Care* 2012;**2**:248-255 doi:10.1136/bmjspcare-2012-000200
- > Hewitt M, Greenfield S, Stovall E. (2005) *From Cancer Patient to Cancer Survivor: Lost in Transition*. National Academies Press: Washington DC.
- > Hughes DC, Lenihan DJ, Harrison CA, Basen-Engquist KM. (2011) Exercise intervention for cancer survivorship with heart failure. *J Exerc Sci Fit* 9(1), 65-73.
- > McCorkle R, Ercolano E, Lazenby M, Schulman-Green D, Schilling LS, Lorig K, Wagner EW. (2011) Self-management: Enabling and empowering patients living with cancer as a chronic illness. *CA: A Cancer J Clin* 61(1), 50–62. doi: 10.3322/caac.20093
- > McKay G, Knott VE, Delfabbro P. (in press) Return to work and cancer: The Australian experience. *J of Occup Rehab*.
- > Regan-Smith M, Hirschmann K, Lobst W, Battersby M. (2006) Teaching residents chronic disease management using the Flinders model. *J Cancer Educ* 21(2), 60–62.
- > Smith TJ, Snyder C. (2011) Is it time for (survivorship care) plan B? *J Clin Oncol* 29(36), 4740-4742. doi: 10.1200/JCO.2011.38.8397
- > Von Korff M, Gruman J, Schaefer J, Curry SJ, Wagner EH. (1997) Collaborative management of chronic illness. *Ann Intern Med* 127,1097-1102.
- > Yeh ETH, Bickford CL. (2009) Cardiovascular Complications of Cancer Therapy: Incidence, Pathogenesis, Diagnosis, and Management. *J Am Coll Cardiol* 53(24),2231-2247. doi:10.1016/j.jacc.2009.02.050



Flinders
UNIVERSITY

inspiring achievement
www.flinders.edu.au