Shifting Roles and Models in Community-Based Primary Health Care and the Power of Co-design

RUTA VALAITIS RN, PHD
DOROTHY C. HALL CHAIR IN PRIMARY HEALTH CARE NURSING
MCMASTER UNIVERSITY
Objectives

1. Describe the development of a new model of community-oriented primary health care involving volunteers as an extension of the provider team that is currently being tested in Canada (HealthTAPESTRY)

2. Illustrate the application and value of the persona scenario method in the co-production of a complex primary care intervention – for HealthTAPESTRY

3. Explore a framework for adaptation of interventions that has been shown to be effective for spread of effective interventions to other settings.
Key Messages

Slow down! Work closely with end users:

1. Before you invent a new role or model for implementation
2. Before you implement an ‘effective’ intervention in a new setting/population.

Co-design to invent

Co-design for scale & spread
Scale Up and Spread

Scale up: “deliberate efforts to increase the impact of health service innovations successfully tested in pilot or experimental projects so as to benefit more people and to foster policy and program development on a lasting basis.”

(ExpandNet - a World Health Organization initiative:
http://apps.who.int/iris/bitstream/10665/44180/1/9789241598521_eng.pdf)

Spread: “extend widely over a large area, or to cause something to do so.”

Dissemination: the large-scale roll-out, scale up, or spread of an innovation following its implementation in a limited number of settings.

Why Co-Design?

The blind men and the elephant
Co-Design

1. Ensures programs and services are closely aligned to user needs and requirements.

2. Design for (users as the main input in the design process), design with (users being involved in providing solutions to design problems), and design by (users actively participating in design).

3. Focus on:
   - designing experiences rather than systems and processes
   - relationship between service providers and service users in design of service interventions
   - knowledge of those external to the organization who can contribute.

Health TAPESTRY
A Novel Platform for Community-Engaged Team-Based Primary Care

Lisa Dolovich, Doug Oliver, Larkin Lamarche, Gina Agarwal, Tracey Carr, David Chan, Laura Cleghorn, Lauren Griffith, Dena Javadi, Monika Kastner, Jennifer Longaphy, Dee Mangin, Alexandra Papaioannou, Jenny Ploeg, Parminder Raina, Julie Richardson, Cathy Risdon, P. Lina Santaguida, Sharon Straus, Lehana Thabane, Ruta Valaitis, David Price and the Health TAPESTRY team
Funded by

• Health Canada
• Government of Ontario (INSPIREphC)
• The Labarge Optimal Aging Initiative
• The McMaster Family Health Organization
AIM
To foster **optimal aging** for individuals where they live using an **interprofessional primary health and social care** delivery approach that centres on meeting a person’s **health goals** and needs.
VIDEO

Youtube
“HealthTapestry”
Co-design:

Persona Scenario Method

• Participants use their own experiences and perceptions to guide the development of complex interventions
• Helps understand how intervention components interrelate

Creating Stories

• Persona scenarios should be “good, coherent stories, which make sense to the storytellers and to the audience – and which therefore generate many, new, and shared understandings and design ideas” (p. 57)

• Madsen S, Nielsen L. Exploring persona-scenarios-using storytelling to create design ideas. In Human work interaction design: Usability in social, cultural and organizational contexts 2010 (pp. 57-66). Springer Berlin Heidelberg.
Method

- Participants’ use their knowledge and experience (as a patient/volunteer/provider) to create:
  1. a fictitious, but believable (authentic) ‘persona’
  2. a ‘scenario” for each ‘persona’ that interacts with program components.

Working in pairs with one assistant per pair...

...and one facilitator
Key considerations

• Have participants introduce themselves to address key questions (comfort with technology, experience with volunteering, etc.)

• Group them into homogenous pairs (or groups of 3) if possible

• Consider readability when preparing your guide (we failed!)

• At least 2 hours needed

• Train facilitators to ensure that they support the process. (Role play)

• Remind participants that they are creating a story – refocus – ask probing questions to enhance the details in the story
Electronic personal health record:

- MyOSCAR is a browser-based Personal Health Record that gives patients access to and control of their personal health information. It helps patients to become more actively involved in the management of their health. Patients are able to share their record with whomever they choose. Patients can allow healthcare providers, family members or other selected individuals to have access to their information for viewing or updating with their consent.

Health and social system navigation support in primary care:

- System navigation is a fairly new concept that is focused on helping patients navigate the healthcare system. It involves coordination of services and providing information to ease barriers and obstacles to care or services. TAPESTRY’s goal is to increase access to health or community-based programs and services that can promote staying healthy at home.

TAPESTRY community volunteers:

- TAPESTRY includes trained community volunteers as one part of its program. Basic health information will be completed by volunteer pairs in the older adult patient’s home. Information will be electronically sent back to the patient’s medical record for follow-up in the primary care office. These trained volunteer pairs may also play a central role to help patients to meet their health goals. These goals will assist them to stay healthy longer.

An interdisciplinary primary care team, with outreach and support from community-based organizations/services:

- TAPESTRY aims to help us understand how interprofessional teams can be used to better meet the needs of our aging population. This will be done by combining the use of technology, system navigation, and trained TAPESTRY community volunteers, links with specialist care, and partnerships among primary care and community agencies/resources.
STEP 1: Create a Persona (10 minutes)

Give your TAPESTRY linked patient- your “Persona”- some personality. Briefly describe the following:

1. **a name**
2. age, gender
3. education and employment background
4. desires, attitudes about health
5. type and size of community (i.e., large urban/ small rural/metropolitan)
6. number of years as a patient at primary care clinic/office
7. experience with volunteering or working with volunteers
8. comfort and experience with technology
9. current involvement with community services
STEP 2. Create a scenario (20 - 25 minutes)

Create a scenario (or 2) for your persona who is involved in the TAPESTRY Program.

1. How does the patient become involved with TAPESTRY?
2. What are the following people doing in the scenario? (What, where, when, how?)
   1. family or caregivers; primary care providers; community service providers; TAPESTRY community volunteers;
3. How are the ‘components’ interacting? That is, how do individuals relate to each other (patients, primary care team, community agency staff, TAPESTRY community volunteers) and to the technologies (Personal Health Record, Electronic Medical Record, TAPESTRY App)?
4. What happens when all players interact with the program?
5. What happens after the interaction?
6. What are the results / outcomes of this interaction? For community agencies; patients; volunteers; health care providers?
STEP 3. Report back to larger group. (5 minutes per group)

• Tell your story - a high level summary of your persona and scenario/s.
• Record this part!
• With the larger group you can then discuss the common features and those that are unique and get feedback on this.
TAPESTRY Participants

• 14 discussion groups over 5 months
• 70 participants
  • patients (n=15),
  • healthcare providers/community healthcare providers (n=29),
  • community service providers (n=12),
  • volunteers (mature and younger) (n=14)
• Groups ranged from 3 to 8 participants
• 2 to 4 researchers present
• 33 persona / scenarios generated
Example of a Volunteer Persona

• So, Steve’s previous experience with agencies wasn’t very much. We said that Steve was new to this. He had been at a nursing home, but never at something like a TAPESTRY program. His comfort level with technology, he’s younger so he’s pretty good at it. His hopes and fears about healthcare? He’s passionate about the elderly, so he wants them to have access to different things, so that’s why he wanted to get involved with this. He wants to improve their quality of life, He’s interested in pursuing a job or career involved with the elderly. His potential fears? Maybe not being able to relate to elderly or older adults who he’s interacting with. And this city has a high immigrant population so there may be language barriers; that’s something that Steve was concerned about.
Example of a Volunteer Scenario

Steve found out about TAPESTRY in an in-class presentation at the beginning of class. So what they had to do for training was a 2-day presentation, so basic assessments and data collection, it was pretty much all about TAPESTRY. It told them how to act with their patients that they’re working with, also what maybe boundaries that they have, the safety procedures that they have to go in with, they have to have a certain amount of, safety when entering a person’s house; they’re always in a buddy system. We also suggested a safety button to press in case of emergency. So they go in with the second person who is either like them... but they first go in, at least 3 visits with a mentor who’s been with the program for a while. So the first 3 visits they go with the mentor, see the patient, introduce themselves, have an intro visit. Then after the 3 visits that they feel comfortable, they’re paired with another new recruit who’s also been 3 visits with the mentor and they go together and start going to the patient regularly.

• ACTIONS (Processes) ITEM
Figure 1 – Process for Data Analysis

1. Focus group
2. Transcript
3. Coded into descriptive nodes
4. Organized into emergent themes

- Nodes examined, determined ACTION and ITEM needed to achieve
- Items reviewed, removed duplications, considered for feasibility, timing and scope

5. Actions
6. Items (400)
7. Considered
8. Novel

McMaster University
Health Tapestry
Analysis

• Coded transcripts → over 400 generated items.

• Items grouped together into 48 themes (definitions).
  • E.g., “Have a nurse review the volunteer-collected patient information to determine if anything needed to be addressed immediately” was grouped with similar items → “Triaging”.

• Themes organized under **4 intervention components** of the TAPESTRY program and the Category **Patients**
<table>
<thead>
<tr>
<th>QUOTE FROM PARTICIPANT WHILE DISCUSSING THE PROGRAM COMPONENT OF VOLUNTEER</th>
<th>NODES</th>
<th>ACTIONS</th>
<th>SPECIFICATIONS</th>
<th>ITEMS</th>
</tr>
</thead>
</table>
| “We see the role for the volunteers being the information gatherer. But the volunteer really does need to communicate with the physician too. And this could be through electronic means, giving feedback to the physician and the physician will ultimately make the decision about whether an appointment is needed and inform either the patient or the volunteer” (Scenario 1, Patient Group 1) | Volunteer acts as an information gatherer and communicates patient information to the physician who makes the decisions | Integrate a functional application that gathers information directly into the electronic medical record | • Tablet computer  
• Application with information-gathering tools  
• Volunteer training program | Train volunteers on how to gather information |
| Volunteer provides information to the physician electronically | Volunteer sends electronic updates using the application to the clinical team weekly, monthly, or after each visit | | • Electronic collection form  
• Secure system to transfer updates  
• Schedule for sending information | |
| Physician receives volunteer information electronically and decides whether an appointment is needed | Physician uses volunteer assessment information | | • Follow-up on expectations of assessment results  
• Mechanism to provide most relevant information to the physician; mechanism for physician to get additional information if required | |
More analysis

• Themes examined to identify cross-cutting concepts (that applied to a number of themes) which highlighted interactions between components.
Cross-cutting Concepts

• Enrolment and publicity
• Team use of information
• Role clarity
• Privacy and confidentiality

• Logistics
• Using the personal health record
• Communication
• Connection

Themes examined to identify cross-cutting concepts (that applied to a number of themes) which highlighted interactions between components
## Value Added

<table>
<thead>
<tr>
<th>Components</th>
<th>Theme examples</th>
<th>Number of Novel Items</th>
<th>Number of Considered Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Team</td>
<td>TAPESTRY champion</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Volunteers</td>
<td>Procedures for volunteer visits</td>
<td>1</td>
<td>4</td>
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<tr>
<td>Patient</td>
<td>Patient/Volunteer relations</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>....</td>
<td>....</td>
<td>.....</td>
</tr>
<tr>
<td>TOTAL</td>
<td>182</td>
<td>224</td>
<td></td>
</tr>
</tbody>
</table>
Value Added

• **New ideas**: Some themes yielded more new ideas than others (e.g. volunteer training)
• **Refinement** of the intervention
• **Confirmation** of researchers’ ideas for the intervention (e.g. role of the volunteer coordinator).
Challenges

Recruitment and scheduling patients and agencies is time consuming and heavy on resources.

Data collection and analysis is not simple
Experiences and Preferences Informed Design

Clinician groups
• Articulated clinical needs
• Knowledgeable about clinic and team functioning
• Knowledgeable about potential barriers to clinic efficiency

Patients
• Brought perspectives that others may not have understood or known about
• Directed program development taking account of their needs, perceptions, and restrictions

Community agency participants
• Reminded the team of the need for inter-agency community and collaboration, as well as highlighting fiscal realities of smaller agencies who depend on referrals to receive funding

Volunteers
• Reminded the scientific team of the potential range of roles that they could play within TAPESTRY (data collection, support of older adults, linkage to community agencies).
RCT to evaluate effectiveness and implementation and sustainability of TAPESTRY
2 Key Messages

• **Slow down! Work closely with end users:**
  1. Before you invent a new role or model for implementation
  2. Before you implement an ‘effective’ intervention in a new setting.

Co-design to invent

Co-design to adapt for scale & spread
Using the collaborative intervention planning framework for intervention planning, implementation and evaluation

- **Community-based participatory research principles**
  - E.g., capacity building, ownership, shared health concern

- **Intervention mapping (IM) procedures**, to inform intervention adaptations, modify and assess feasibility and acceptability of an existing intervention
  - E.g., literature reviews, data collection, interviews

**Population:** Hispanics with Serious Mental Illness

**Aim:** to improve the physical health of Hispanics with serious mental illness who are at risk for CVD using a care manager.

**The Intervention:** Care managers who:

- Do not provide direct medical services
- Work with patients in the outpatient mental health clinic to provide education and activation
- Connect patients to primary care
- Coordinate a patient’s medical care between mental health and primary care

**Shown Effectiveness:** RCT - rate of receipt of preventive medical care X2 & improved quality of cardio-metabolic care and mental-health-related QoL

Socio-cultural Considerations for Adaptation

- **Surface level modifications**: match intervention materials & messages to characteristics of the new population.

- **Deep-level modifications**: consider patients’ cultural values, understandings, and preferences that impact core intervention elements.

System level Considerations for Adaptation

System-Level Factors

• Originally developed for RNs - RNs in short supply
  – Social workers outnumber RNs 2.5 to 1

• Medical care was not delivered -->
  • Intervention modified for a social worker
    • Work closely with minority families
    • Have counselling skills
    • Deliver 60% of mental health care in the US
    • Can bill for care management.

ADAPTATION NEEDED!

• Social workers required training on management of health needs of those with serious mental illness
6 steps of Intervention Mapping

1. Problem analysis
2. Review of intervention objectives and theoretical foundations
3. Modification of intervention methods and strategies
4. Development of a revised intervention
5. Development of an implementation plan
6. Evaluation

**Logic Model**

CAST Study
Transition from Hospital to Home

Key Messages

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Co-design to invent

Co-design to scale and spread
THANK YOU!

Ruta Valaitis RN, PhD

Associate Professor, School of Nursing
Dorothy C. Hall Chair in Primary Health Care Nursing
Associate Member of the Department of Family Medicine
Deputy Director, WHO Collaborating Centre for Primary Care and Health Human Resources
HSC 3N25E 1280 Main Street W.
McMaster University
Hamilton ON L8S4K1

905-525-9140 ext 22298
ruta@mcmaster.ca