Beyond Hepatitis: Experiences to Mobilize Society

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This Talk

- Role of communication in mobilizing society
- Examples and strategies
- Implications for building a hepatitis-concerned movement
• Beyond awareness…
• Foster behavioral, social, policy, and organizational change
• Facilitate community-driven and multisectoral processes and interventions
• Relies on systematic frameworks for planning
• “I heard it from many places”
Sustainability and Community Ownership: Two Intersecting Concepts

Sustainability
- Goods, services, and actions
- Set of social, environmental, and economic values and conditions
- Specific health and social goals
- Pre-requisite to the effectiveness of all interventions
- Has to do with long-term planning
- Key in system-framing
- Intersecting with behavioral/social change
- Requires “community” ownership, engagement, endorsement
- A key concept in public health, healthcare, development, communication

Community ownership and engagement
- A pre-requisite to sustainability

Services, norms, behaviors, policies and others. “can be undermined all together if local populations experience them as inappropriate or unjust…”

Ref: Leach, Scoones, and Stirling, 2009; Schiavo, 2013; Schiavo, Leung, and Brown, 2014; Schiavo, 2009; UNICEF, 2010
A new concept of “community”

“A new concept of 'community', is one that is composed not only of community residents but also all the stakeholders who live, work, and operate in a given geographical area. (Schiavo, 2013) This includes all kinds of businesses, institutions, municipal services, policy makers, government services – all of which have reasons to care about the health and prosperity of that specific neighborhood, city, or locality.” (Schiavo, 2013).”

-- Schiavo, Padgaonkar, Cooney, Cruz, and Health Equity Initiative, 2016. All rights reserved.
## Looking at a Disease–Based Approach to Health versus a SODH Approach

### Disease-Based Approach
- Main focus on Symptoms/medical causes Primary audiences and key influencers
- Often oblivious of other root causes that may facilitate adoption of healthy behaviors
- May lack sustainability even when it involves multiple sectors and action areas

### SDOH Approach
- Incorporates in–depth analysis of living and working environment
- Addresses root causes in addition to individual and community behaviors
- Multi-sectoral by definition
- Health & healthcare as part of an integrated approach to community development (and vice versa)
- Community engagement

Example: HepC Test

Clinicians need to recommend testing, discuss barriers and misconceptions, resources

Family members, friends, and co-workers encourage testing and get tested themselves

Community organizations provide support, information, and resources

Local companies, hospitals, community and religious leaders work together to provide culturally competent information/encourage new social norms and/or remove barriers to testing (e.g., potential stigma)

Local policies prioritize and funds easy access to testing/information

Baby boomer to be tested for HepC

Source: Adapted from Schiavo, 2015. All rights reserved.
Health Equity is providing every person with the same opportunity to stay healthy and/or effectively cope with disease and crisis regardless of their socio-economic conditions, race, gender, age, social status, living and working environment, and other socially determined factors.

Health Equity Initiative/Schiavo, 2012
Some Examples
WHY COMMUNITY ENGAGEMENT MATTERS: EXAMPLE 1

In Absence of Community Engagement, It’s Difficult to Address Social Values and Norms!

“It was difficult to get people to stay away from their churches” – SARS Canada

“People won’t accept not to visit sick people” – Avian flu, Nigeria

“Traditional practices of touching and sleeping with dead people as a last expression of respect were important in many communities” – Ebola, Southern Sudan

“There is a different understanding of social and physical distancing [required to protect people from the flu] within different ethnic groups” – United States
WHY COMMUNITY ENGAGEMENT MATTERS: EXAMPLE 2
SELECT RESULTS FROM A SYSTEMATIC REVIEW

29 studies from 16 countries included in review

Quality of studies “High” to “Moderate to Low” (CASP); “High” to “Low” (applicability to LMICs)

• Most promising interventions and themes/areas
  – Community-based/participatory interventions
  – Multi-component/ multisectoral approaches to intervention design
• Focus on SDOH/health equity much needed within future assessments
  – Most eligible studies focus on assessing results re: health and social behaviors or intermediate steps
  – Very few studies had implications for health system-related outcomes or environmental health impact or improved health service delivery

COMMUNITY AND CITIZEN ENGAGEMENT IN RISK COMMUNICATION: KEY LESSONS

- Central role of communication
- Community leaders **engagement**
- Cultural competence/trust
- Tailored/group-specific efforts
- Focus on **at-risk groups**
- Message consistency
- Communication **readiness**
- Credibility

- **Preparedness**/comm plans
- Multisectoral **alliances**
- Clarity of terminology
- Focus on **special populations**
- Expand partnerships with communities/religious and community leaders

- **Public/community mistrust**
- Social norms difficult to change without community **engagement**
  Communication hoaxes
  National and global communication **coordination** and **readiness**

**Mistrust** in official information
Central role of **engagement** of traditional and religious leaders
- Complex concepts requires **culturally competent** tools
- Empowering **community networks**
- Integrating communication/social mobilization with RRT and communities

Using participatory planning to engage key stakeholders in the development of an evaluation framework for a national initiative to eliminate chronic malnutrition among children/pregnant women - UNICEF/Ministry of Health of Rwanda – via Strategic Communication Resources

Establishing a road map for malaria prevention via a stakeholder- and consensus-driven process and community guidance- UNICEF/Ministry of Health of Angola – via Strategic Communication Resources

Empowering communities and/or patients via HCD processes to:
- Reduce mortality of Kalazar in rural areas
- Design information for low-literacy cancer patients
- Form a ALS association with healthcare providers
- Design resources to improve patient-provider interactions
- Rhodia Center for Socio-Medical Studies
Building community-campus partnerships to prevent infant mortality: Lessons learned from building capacity in four U.S. cities

Bringing this back to Hepatitis
Bringing this back to Civic Engagement on Hepatitis

Applying lessons learned from other experiences

- Keep an open mind
- Consider potential bias within different stakeholders
- Map influentials
- *Ownership* and *Interactivity* are key for all planning processes
- Set the right expectations, don’t overpromise
- Be inclusive of vulnerable and underserved populations
- Find role models!
- Don’t stop at intervention design! Engage communities in all phases of intervention and research design!
It starts with you –

- Foster a culture of engagement in your organization and community
- Keep a sharp focus on community benefits and social change
- Advocate for increasing funding and new policies!

We all want the epidemic to be silent – no more!
Tell me and I'll forget; show me and I may remember; involve me and I'll understand.
Thank You!
Obrigada

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