Caregiver and Provider Perspectives: A Participatory Empowerment Approach to Assess Problems of Childhood Asthma

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Introduction

The Problem of Asthma

– Asthma is a chronic lung disease

– 1 in 3 children on the Southside of Chicago has asthma

– Asthma diagnosis in Chicago greatest where >98% African American, and >40% below poverty line

– Nation spends 12 billion dollars annually on asthma-related costs

– Nation's children miss total of 10 million school days due to asthma

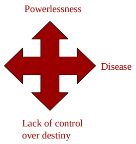
– Etiologies hypothesize genetics and environment

– Classifications include mild intermittent through severe persistent

– Treatments and prevention of exacerbations with persistent asthma include twice a day medicinal regimens, difficlt to adhere to

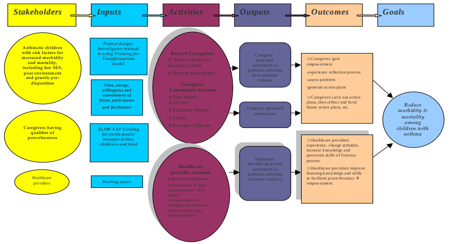
The Problem of Powerlessness

- Living in Poverty
- Low in hierarchy
- High physical demand
- Low control
  - Perceived/learned helplessness
  - Actual/no economic or political voice
- Chronic stress
- Lack of social support
- Lack of resources



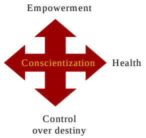
Powerlessness is a risk factor for morbidity when attempting to control any chronic disease, including asthma

Asthma Empowerment Logic Model



Empowerment: The Opposite of Powerlessness

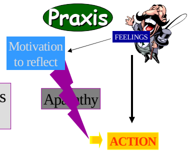
Sense of community
Participation
Decision making
Motivation to act
Community actions → empowerment
Increased empathy
Stronger social networks
Psychological empowerment
Self-efficacy to act
Community competence
Transformed conditions
Improved health policies
Resource access/quality
Belief in group action
Political efficacy



HELP

LISTEN → Facilitate thinking, speaking & acting (mobilize individual and community resources) → Empowerment → Change → Health (well-being) for all

Give to, Do for, Tell → Dependence → Status Quo



Conscientization: Critical consciousness
Praxis: Reflective action

Hypothesis

Asthmatic caregivers will act to improve the quality of his or her child's asthma through participation in a Freirian community empowerment process.

Further, healthcare providers, after experiencing and listening to a didactical explanation of a Freirian empowerment process model will demonstrate change in attitudes, knowledge and skills regarding listening to asthmatic caregivers and facilitation of community empowerment.

Research Questions

1) How will asthmatic caregivers engage in a Freirian community empowerment process?
2) Through brief experience and explanation of a Freirian empowerment process model, will healthcare providers demonstrate change in attitudes, knowledge and skills regarding listening to asthmatic caregivers and facilitation of community empowerment?
3) How will asthmatic caregiver and pediatric provider participants similarly and dissimilarly assess problems of childhood asthma?

Results

Caregivers' and Providers'Assessments of ProblemsRegarding Childhood Asthma

Similarities between caregivers and providers

–Uncontrolled asthma, its existence
–Morbidity: child self-esteem, caregiver stress
–Medications, that they exist
–Triggers

Dissimilarities between caregivers and providers

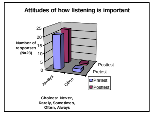
–Chronic asthma
•Caregivers: increasing prevalence
•Providers: focus on why child was having asthma exacerbation
–Morbidity
•Caregivers: damper on child's and family's life, powerlessness
•Providers: single parent stress, disruption of child's education
–Meds
•Caregivers: fear of addiction, side-effects
•Providers: prescription of? and compliance
–Triggers
•Caregivers included pollution

Knowledge of listening

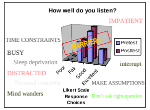
Pretest
- Eye contact 48%
- Repeat 30%
- Ask questions 22%
- Do not interrupt 17%

Posttest
- Eye contact 17%
- Repeat 35%
- Ask questions 35%
- Do not interrupt 13%
- Do not judge 17%
- Empathy 9%
- Summarize 9%

Attitudes of listening



Perceived listening skills



Knowledge of community empowerment

Pretest
- Individuals vs. community
- Self-help or sufficiency
- For the greater god
- Education
- Effects change
- Giving information, resources, access to healthcare

Posttest
- Method to combat powerlessness
- Listening
- Identifying problems
- Emotion
- Motivation
- Action
- Evaluation
- Research
- Praxis
- Giving

Attitudes of community empowerment

Barriers to implementing process
- Time
- Funding
- Work
- Dedication
- Patience
- Community participation

Perceived skills/intended application of community empowerment

Intent among providers to use process
- Pretest
  - Education
  - Motivate others to listen as M.D.
  - Promote access/Provide healthcare
  - Increase medical compliance
  - Community service

Intent among providers to use process
- Posttest
  - Listen
  - Identify community problems in healthcare
  - Empower patients
  - Community empowerment
  - Make help helpful
  - Education

Discussion

Limitations

- Comparing caregiver and provider problem assessments regarding childhood asthma: two demographically, culturally different groups
- Time between pretests and posttests 48 hours
- Low N (5 caregivers retained)
  – Non-response error
  – Cannot generalize findings
- Reflection-action cycle incomplete

Challenges of Design

- Implementation of process: time consuming
- Power dynamics: difficult to eliminate
- Codes and reflection
- Measuring empowerment: must have means for accurately measuring for meaningful qualitative or quantitative data in terms of understanding efficacy of health empowerment model

Public Health Implications

- Empowerment process can address issues of powerlessness, which worsens disease processes and exaggerates health disparities
- Community forums may be efficient and efficacious venue for listening and facilitating empowerment
- With achievement of empowerment
  - Diseases will be less morbid
  - Medication compliance will improve
  - Disease prevalence will decrease
  - Health disparities will diminish

Future Recommendations

- Continue current project
  - Obtain good pre and post intervention measures of empowerment
  - Change recruitment strategies
  - Progress to community action and continue reflection-action cycle
- Peer facilitation: community members facilitate forums
- Increase number of training opportunities for healthcare providers

MAKE SURE THAT YOUR HELP IS HELPFUL

ALWAYS COMBINE RELIEF WITH EMPOWERMENT

Methods

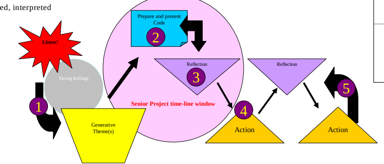
Participants

– 21 asthmatic caregivers; 5 retained
- Community forums once weekly for six weeks
- Facilitators implemented Freire philosophy and participants
  – Facilitated assessment of problems related to childhood asthma
  – Began action planning
  – Ethnographer recorded caregiver participation; this was analyzed and interpretted

– 42 pediatric healthcare providers; 23 retained
- First morning report – providers participated in experience of Freire process and generated problem list of childhood asthma
- Second morning report – providers endured didactical explanation of process
- Pre and Posttest distributed, collected, analyzed, interpreted

Paulo Freire methods described by Anne Hope and Sally Timmel:

1. Listen to community for generative theme
2. Prepare code that represents generative theme and present back to community members
3. Facilitate code so community members reflect, assess, create action plans to overcome problems
4. Community members take action
5. Community reflects on actions and repeats action-reflection cycle



Outline of Paulo Freire Philosophy

Philosophy of methodology	Description of how to implement	Implications for this project
Participants have strengths, abilities inside of them to address their own problems	Facilitators identify and recognize through incorporating into forum exercises community members' strengths and abilities.	Facilitators presumed participant strengths to include abilities to identify problems of asthma, name root causes of problems, plan approaches to solve their own problems and, ultimately, take action to improve or solve their problems
e*MOTI* on equals *MOTI* vation	Facilitators/animators are responsible to listen to community generative themes	Childhood asthma is a problem on the Southside of Chicago, generating strong feelings among both caregivers and healthcare providers
Community praxis	Reflection without action is useless; action without reflection is futile. Intentional reflective action is praxis. Groups enact effectiveness of empowerment more than individuals.	The scope of this project is assessing problems and root causes. Beyond this will be action planning, action and reassessment.

Community Forum Design

Transformation for Health

- Learning Climate: Values participant, breaks down traditional power structure of teacher-learner
  – Room arrangement circular
  – Small group and large group activities to create more "air time" for each participant
  – Newsprint/flip-chart honor participant responses
  – Participatory evaluation
  – Listening is main focus of facilitator
- Building trust, builds community
- The process is PARTICIPATORY

Generative Themes

Facilitator's role is to identify community issues that generate strong emotions among community members.
– Listen! Listen! Listen!
– Important issues generate energy to break through apathy

Code

- Presents a familiar problem in a concrete manner
- Must be presented without a solution
- Can be in the form of
  – Skit/play
  – Picture/photo
  – Cartoon
  – Artwork
  – Stories/prose
  – Etc.

Example of Code

Example of Code run with Caregivers of Asthma

Facilitating a Code

What do you see happening?
What is the problem?
How does this happen in your or our lives?
– How does it feel?
What are the root causes?
– Why, Why, Why!!!?
What can we do about this problem?
Who will do it? When? Where?

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References

Adams, R.J., Fuhlbrigge, A., Finkelstein, J.A., Lozano, Pl., Livingston, J.M., Weiss, K.B., & Weiss, S.T. (2001). Impact of inhaled anti-inflammatory therapy on hospitalization and emergency department visits for children with asthma. *Pediatrics, 107(4)*, 706-711.
Akinbami, L.J. & Schoendorf, K.C. (2002). Trends in childhood asthma: Prevalence, health care utilization, and mortality. *Pediatrics, 110*, 315-322.
Berhman, R.E., Kliegman, R.M., & Jenson, H.B. (2000). *Nelson Textbook of Pediatrics 16th Edition.* Philadelphia, PA: W.B. Saunders Company.
Braithwaite, R.L. & Lythcott, N. (1989). Community empowerment as a strategy for health promotion for black and other minority populations. *Journal of the American Medical Association, 261(2)*, 282-283.
Braun-Fahrlander, C., Riedler, J., & Herz, U. (2002). Environmental exposure to endotoxin and its relation to asthma in school-age children. *New England Journal of Medicine, 347*, 869-877.
Baskshee, K. (1997). Impact of roles of women on health in India. *International Journal of Gynecology & Obstetrics, 58*, 35-42.
Connor, A., Ling, C.G., Tuttle, J., & Brown-Tezera, B. (1999). Peer education project with persons who have experienced homelessness. *Public Health Nursing, 16(5)*, 367-373.
Covering Kids & Families Illinois (data from 2002). Chicago, Illinois. Website: http://www.ilmaternal.org/CoveringKids.
Endicott, , L., Corsello, P., Prinzi, M., Tinkelman, D.G., & Schwartz, A. (2003). Operating a sustainable disease management program for chronic obstructive pulmonary disease. *Lippincott's Case Management, 8(6)*, 252-262.
Expert Panel Report 2: Guidelines for the Diagnosis and Management of Asthma. National Institutes of Health Publication 97-4051, 1997.
Falf-Rafael, A.R. (2001). Empowerment as a process of evolving consciousness: A model of empowered caring. *Advanced Nursing Science, 24*, 1-16.
Farmer, Paul (1999). *Infections and Inequalities.* Berkeley, CA: University of California Press.
Ford, M.E., Edwards, G., Rodriguez, J.L., Gibson, R.C., & Tilley, B.C. (1996). An empowerment-centered, church-based asthma education program for African American adults. *Health & Social Work, 21(1)*, 70-75.
Freire, Paulo (1970). *Pedagogy of the Oppressed.* New York, NY: The Continuum Publishing Company.
Freudenberg, N., Eng, E., Flay, B., Parcel, G., Rogers, T., & Wallerstein, N. (1995). Strengthening individual and community capacity to prevent disease and promote health: In search of relevant theories and principles. *Health Education Quarterly, 22(3)*, 290-306.
Fulton, Y. (1997). Nurses' views on empowerment: A critical social theory perspective. *Journal of Advanced Nursing, 26*, 529-536.
Gallagher, S. (1997). Surviving redesign: Basic concepts of patient-focused care and their application to WOC nursing. *Journal of Wound, Ostomy, & Continence Nursing, 24(3)*, 132-136.
Goodman, R.M., Speers, M.A., McLeroy, K., Fawcett, S., Kegler, M., & Parker, E. et al (1998). Identifying and defining the dimensions of community capacity to provide a basis for measurement. *Health Education & Behavior, 25(3)*, 258-278.
Grant, E.N., Daugherty, S.R., Moy, J.N., Nelson, S.G., Piorkowski, J.M., & Weiss, K.B. (1999). Prevalence and burden of illness for asthma and related symptoms among kindergartners in Chicago public schools. *Annals of Allergy, Asthma, & Immunology*, 83(2), 113-20.
Gray, D.L., Langefeld, C.D., Golden, M.P., & Orr, D.P. (1993). Impact of resident participation in a multidisciplinary diabetes team. *Diabetes Care, 16(5)*, 705-707.
Guill, M.F. (2004). Asthma update: Epidemiology and pathophysiology. *Pediatrics in Review, 25(9)*, 299-304.
Harding, S. (1993). *The "Racial" Economy of Science: Toward a democratic future.* Bloomington, IN: Indiana University Press.
Healthy People 2010 website: http://www.healthypeople.gov/Publications/
Hennessy-Harstad, E.B. (1999). Empowering adolescents with asthma to take control through adaptation. *Pediatric Health Care, 13*, 273-277.
Hope, Anne & Timmel, Sally (1984). *Training for Transformation: A Handbook for Community Workers, Book I, II, III.* Gweru, Zimbabwe: Mambo Press.
Isreal, B.A., Checkoway, B., Schultz, A., & Zimmerman, M. (1994). Health Education and Community Empowerment: Conceptualizing and Measuring Perceptions of Individual, Organizational, and Community Control. *Health Education Quarterly*, 21(2): 149-170.
Kai, J. & Crosland, A. (2002). Perspectives of people with enduring mental ill health from a community-based qualitative study. *British Journal of General Practice, 51*, 730-736.
Kiser, M., Boario, M. & Hilton, D. (1995). Transformation for health: A participatory empowerment education training model in the faith community. *Journal of Health Education*, 26(6), 361-365.
Knowles, Malcolm (1970). *The Modern Practice of Adult Education: Andragogy versus Pedagogy.* New York, NY: Association Press.
Labonte, R. (1994). Health promotion and empowerment: Reflections on professional practice. *Health Education Quarterly, 21(2)*, 253-268.
Lester, L.A., Rich, S.S., Blumenthal, M.N., Togia, A., Murphy, S., & Malveaux, F. et al (2001). Ethnic differences in asthma and associated phenotypes: Collaborative study on the genetics of asthma. *Journal of Allergy and Clinical Immunology, 108(3)*, 357-362.
McKnight, J.L. (1985). Health and empowerment. *Canadian Journal of Public Health, S76*, 37-38.
McQuiston, C., Choi-Hevel, S., & Clawson, M. (2001). Protegiendo Nuestra Comunidad: Empowerment Participatory Education for HIV Prevention. *Journal of Transcultural Nursing, 12(4)*, 275-283.
Minkler, M. (2000). Using participatory action research to build healthy communities. *Public Health Reports, 115*, 191-197.
Minkler, Meredith & Wallerstein, Nina (2003). *Community-Based Participatory Research for Health.* San Francisco, CA: Jossey-Bass.
Muhib, F., Lin, L., Steuve, A., Miller, R., Ford, W., & Johnson, W., et al (2001). A Venue-Based Method for Sampling Hard-to-Reach Populations. *Public Health Reports, S116*, 216-222.
Neil, J.A. & Munjas, B.A. (2000). Living with a chronic wound: The voice of sufferers. *Ostomy Wound Management, 46(5)*, 28-38.
Patton, M. (2002). *Qualitative research & evaluation methods.* Thousand Oaks, CA: Sage Publications, Inc.
Persky, V.W., Slezak, J., Contreras, A., Becker, L., Hernandez, E., Ramakrishnan, V., & Piorkowski, J. (1998). Relationships of race and socioeconomic status with prevalence, severity, and symptoms of asthma in Chicago school children. *Annals of Allergy, Asthma, & Immunology, 81*, 266-271.
Powell, D.L. & Steward, V. (2001). Children: The unwitting target of environmental injustices. *Children's Environmental Health, 48(5)*, 1291-1304.
Rappaport, J. (1981). In praise of paradox: A social policy of empowerment over prevention. *American Journal of Community Psychology, 9(1)*, 1-25.
Rappaport, J. (1995). Empowerment meets narrative: Listening to stories and creating settings. *American Journal of Community Psychology, 23(5)*, 795-807.
Salant, P. & Dillman, D. (1994). *How to conduct your own survey.* New York, NY: John Wiley & Sons, Inc.
Sammons, W.A. & Lewis, J. (2001). Helping children survive divorce. *Contemporary Pediatrics, 18(3)*, 103-112.
Syme, S.L. & Berkman, L.F. (1976). Social class, susceptibility and sickness. *American Journal of Epidemiology, 104(1)*, 1-8.
Triggs, E.G. & Perrin, E.C. (1989). Listening carefully: Improving communication about behavior and development. *Clinical Pediatrics, 28(4)*, 185-192.
United States Census website: http://censtats.census.gov/pub/Profiles.shtml
Varcoe, C. (2002). Abuse obscured: An ethnographic account of emergency nursing in relation to violence against women. *Canadian Journal of Nursing Research, 32*, 95-115.
Wallerstein, Nina (1992). Powerlessness, empowerment, and health: Implications for health promotion programs. *American Journal of Health Promotion, 6(3)*, 197-204.
Wallerstein, Nina (1999). Power between evaluator and community: Research relationships within New Mexico's healthier communities. *Social Sciences & Medicine, 49*, 39-53.
Wallerstein, Nina (2000). A participatory evaluation model for healthier communities: Developing indicators for New Mexico. *Public Health Reports, 115*, 199-204.
Wallerstein, Nina (2002). Empowerment to reduce health disparities. *Scandinavian Journal of Public Health, 59*, 72-77.
Wallerstein, N. & Bernstein, E. (1988). Empowerment education: Freire's ideas adapted to health education. *Health Education Quarterly, 15(4)*, 379-394.
Wallerstein, N. and Bernstein, E (1994). Introduction to Community Empowerment, Participatory Education and Health. *Health Education Quarterly, 21(2)*, 141-148.
Walters, V. & Charles, N. (1997). "I just cope from day to day": Unpredictability and anxiety in the lives of women. *Social Science & Medicine, 45(11)*, 1729-1739.
Wang, C.C., Burris, M.A., & Ping, X.Y. (1996). Chinese village women as visual anthropologists: A participatory approach to reaching policymakers. *Social Science in Medicine, 42(10)*, 1391-1400.
Weiss, K.B., Gergen, P.J., & Hodgson, T.A. (1992). An economic evaluation of asthma in the United States. *New England Journal of Medicine, 326(13)*, 862-866.
Weiss, K.B., Sullivan, S.D., & Lyttle, C.S. (2000). Trends in the cost of illness for asthma in the United States, 1985-1994. *Journal of Allergy and Clinical Immunology, 106(3)*, 493-499.
Wissow, L.S. & Roter, D.L. (1994). Pediatrician interview style and mothers' disclosure of psychosocial issues. *Pediatrics, 93(2)*, 289-295.
Wolf, R.L., Berry, C.A., & Quinn, K. (2003). Development and validation of a brief pediatric screen for asthma and allergies among children. *Annals of Allergy, Asthma, & Immunology, 90*, 500-507.
Yancey, A., McCarthy, W., & Leslie, J. (1998). Recruiting African-American Women to Community-based Health Promotion Research. *American Journal of Health Promotion, 12(5)*, 335-338.
Zimmerman, M.A. & Rappaport, J. (1988). Citizen participation, perceived control, and psychological empowerment. *American Journal of Community Psychology, 16(5)*, 725-750.
Zimmerman, M.A. (1990). Taking Aim on Empowerment Research: On the Distinction Between Individual and Psychological Conceptions. *American Journal of Community Psychology, 18(1)*, 169-177.