

"Capacity Building for Leaders of Self-help Groups in Hong Kong" Research findings

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Cancer Link

Hospital Authority

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Patient Self-help Groups (SHG) in Hong Kong

People with similar conditions grouped together

- Co-walker support
- Community advocacy
- Social activities

Size of the group: a few to 2000+

Patients themselves are the organization leaders and form the board of committee. They may employ staff to execute services

<https://docs.google.com/file/d/0BynY1Sml4S3AZzh6S25jWEt2Znc/edit?pli=1>

Project Research Questions

Features of good self-help groups in Hong Kong so that leaders can be empowered for better management

Informants

- leaders of self-help groups
- committee members
- social workers

Research Methodology: Focus Groups

6 focus groups

- 4 for leaders
- 1 for members
- 1 for social workers who worked closely with SHGs

Member check on the focus group results on the Patient Alliance platform

Research Finding ONE


SHG must fit the member needs at different stages


Member Needs at Stage 1: JUST GET THE ILLNESS




Features	Needs / Look for	What SHG offers
<p>Immediate Panic / Shock: What exactly is the illness? How worse my situation could be?</p> 	<ol style="list-style-type: none"> 1. Information 2. Co-walker 	<ol style="list-style-type: none"> 1. Knowledge of the illness 2. Understanding and acknowledging the suffering

Member Needs at Stage 2: LEARN TO ACCEPT HERE N NOW




Features	Needs / Look for	What SHG offers
<p>Day to day functioning How can my basic living go on?</p>	<ol style="list-style-type: none"> 1. Functional care plan 2. change of daily routine and habits (ADL vs. IADL) 3. Acceptance the change of body functions 	<ol style="list-style-type: none"> 1. Aid for living or challenges ahead 2. Resource mobilization 3. Mutual support 


Member Needs at Stage 3: LIFE PLANNING




Features	Needs / Look for	What SHG offers
<p>Plan my future After functioning living, what can I do for a better future?</p> 	<ol style="list-style-type: none"> 1. Hope and future 2. Psychosocial needs 3. Relationship with people 	<ol style="list-style-type: none"> 1. Ways to improve the living standard (esteem, life meaning) 2. Mutual support 

Member Needs at Stage 4: TRANSFORMED IDENTITY



Features	Needs / Look for	What SHG offers
<p>Active new identity I want to contribute to the society</p> 	<ol style="list-style-type: none"> 1. Community advocacy 2. Helping people as co-walkers 	<ol style="list-style-type: none"> 1. Platform to serve other peers 2. How to live like others in the community 3. Bigger than self life meaning 4. Mutual support

Research Finding TWO



SHG leaders and committee members should understand role dilemma and nature of SHG


Role Dilemma for Leaders/ Committee Members



ROLES	IMPLICATIONS
Leader/ committee member	Power Responsibility
Patient	Fragility Help seeking
Volunteer	Sub-standard expectation Cannot demand too much

Nature of SHG

- Distinctive from other NGOs
- Staff turnover and change of committee member (every 2 to 3 years) affect operation
- Being big is a double edged sword
- No standard guideline for operation



Implications to SHG Leaders

- Leaders and committee members have clear visions about the SHG development
- Succession and transition plan
- Focus on core business
- Work flow and documentation



Research finding THREE

SHG can further enhance the mutual help functions in all activities



Unique position of SHG: mutual support

Someone to understand

- Some suffering can't be described clearly
- Peer sharing can quickly go into feeling and talk more deeply, and this sharing itself is therapeutic
- The suffering can be truly understood by the other
- "Comfort" (Outsider) vs. "Understand" (Insider)

Observations on activities

CURRENT

- Social programs
- Advocacy
- Mutual support
- Busy in project fulfillment

SUGGESTIONS

- All activities can inject the elements of mutual support all through revitalize member-member bonding

