

Patients as Volunteers: The Paradox of Participation in Patient Self-Help

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Background and Objectives



Patient Self-help in Chronic Disease Management

- With the rapidly aging population and the improvements in health care, **the number of patients with chronic illnesses has increased significantly**, creating great burden to health care system (Chan et al., 1992);
- Management of chronic disease requires **lifestyle changes, physical exercise, persistence , training and support over a long run.**



Patient Self-help in Chronic Disease Management

- The rise of patient self-help or mutual help movement as an **alternative form of community care**, aiming at :
 - a) **empowering** the patient so that they can manage the chronic conditions of themselves and their loved ones; and
 - b) becoming **active agents of change** in the health care system.



Worldwide trend in Patient Self-help

- ✓ United States: Chronic Diseases Self- Management Programme
- ✓ United Kingdom: Expert Patients Programme
- ✓ Canada: Diabetes Self-Management Programme and employed social workers as “health promoters”
- ✓ Australia: Sharing Health Care Initiative



Functions of Self Help Organisation

- Provide **emotional support, information and advice, education and training, direct services and social network** for members;
- Help to better **cope** with everyday difficulties;



Functions of Self Help Organisation

- Function as pressure group to **advocate** on behalf of the patients;
- Enhance sense of belonging and self-**empowerment** for participants.

(Mok & Martinson, 2000; Adamsen & Rasmussen, 2001; Mok, 2001; Yip et al., 2004; Cheung et al., 2005; Mok, et al., 2006; Stang & Mittelmark, 2008; Kelly & Yeterian, 2011)



Characteristics of Self-help Organisations

1) Emphasize on :

- common experience
- mutual help principle
- differential association
- collective will power and belief
- importance of information, and
- constructive action toward shared goals

(Robinson & Henry, 1977)



Characteristics of Self-help Organisations

2) A kind of **peer psychotherapy** :

- personal sharing from survivors is more convincing and helpful than professional support;
- Effective in reducing professional centrism (Rappaport, 1993)



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Characteristics of Self-help Organisations

3) The principle of “**Helper Therapy**”

- Those who help receive the greatest benefits (Gartner & Riessman, 1974), e.g improvement of interpersonal skills, enhancement of self-image and self-competence (Chan et al., 1996; Yip, 2004; Felix-Ortiz et al., 2000).



SELF-HELP ORGANISATIONS IN HONG KONG :

The Alliance of Patient Mutual Help
Organisations



Development of the Alliance of Patient Mutual Help Organisations

- **1991** : Coalition of 16 organisations which were set up in 70s and 80s with the support of university academia
- **1993** : formally registered as a NGO in HK, being tax-exempted
- **Objectives:**
 - a) support the **growth** of patient self help / mutual help group;
 - b) promote **participation** of patient groups in design of **health care policy**;
 - c) **advocate** for patient-centered health care services and
 - d) **participate** in local and international patient **self-help movement**



Characteristics of the Member Organisations

- Out of **130** self-help organisations in Hong Kong, **47** are member organisations of the Alliance with a total of over **40,000** members;
- Member organisations are of **different types of chronic illness**, e.g patient with kidney transplant, stroke, diabetics, Parkinson's disease, etc.;



Characteristics of the Member Organisations

- With **different sizes and scales**, some may be **loose in governance structure** and lack of management system, rules and regulation;
- Chairman and executive committee members are **elected** among the members who are **also patient themselves** and may not have any background in management;



Characteristics of the Member Organisations

- **High participation** of committee members and general members are expected;
- May employ full time or part-time staff, depending on financial affordability;
- **Unstable and limited income** from government, or other sources of funding.



Research GAP

- Past studies focused more on the functions and positive outcomes of participation in self-help groups.

Previous studies tended to IGNORE the Paradoxes of Patient Participation in Self -help Organisation!

Objectives of the Study

- To identify the **paradoxes** of participation in patient self-help;
- To stimulate **more discussion about the necessary support** to patient self-help organisations



Methods

- **Qualitative Study**

(a) 5 Focus group interviews with 22 self-help group leaders who are all members of the Alliance of Patient Mutual Help Organisations;

(b) Expert observation based on the example of The Alliance of Patient Mutual Help Organizations;

(c) Evidence from previous literature

- database : EBSCO host-Academic Search Premier
The Digital Dissertation Consortium

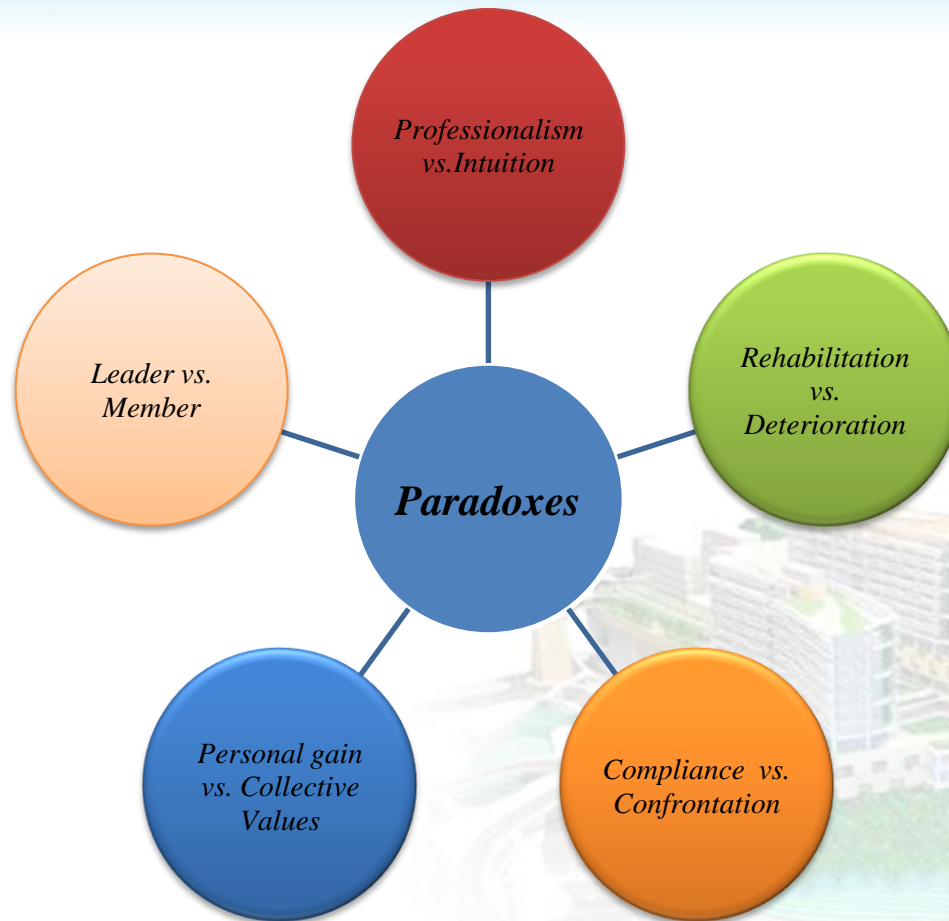


THE FIVE PAIRS OF PARADOX



A HKU project supported by The Hong Kong Jockey Club

Five Pairs of Paradox



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Paradox 1 :

Professionalism vs. Intuition

Who are the leaders?

Led by Professionalism	Led by Intuition
Lack of understanding about patient's experience	With personal experience of the illness, but may still expect support and advice from professionals
Heavy workload of professionals and difficult to lead the patient group	Lack of expertise and knowledge in management
Lack of sense of belongingness and ownership as the patients	Lack of network and power of influence
Minimize patients' role and violate the principles of self-help organisation	Sense of loneliness when totally self-reliance

Paradox 1 : Professionalism vs. Intuition

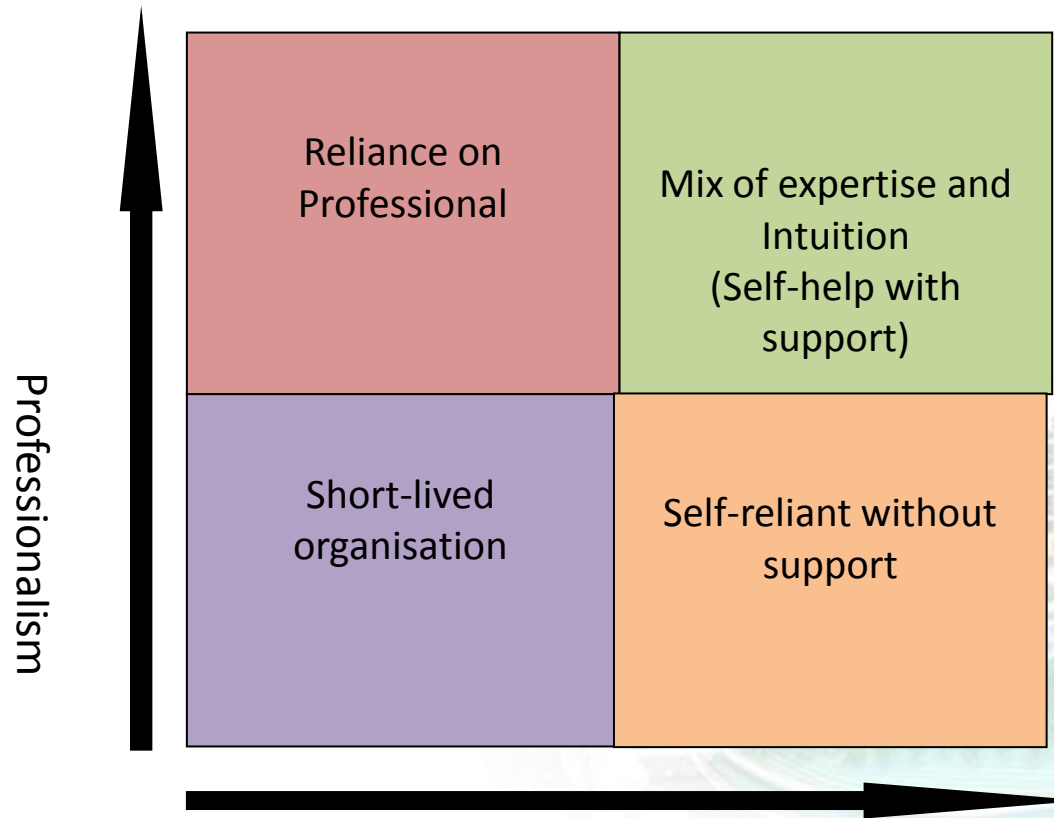
Who are the leaders?

- Over professionalisation may lead to rigid structure and procedure, losing the flexibility and human touch of self-help organisation;
- Though the principle of patient self-help should be upheld, the importance of professional support (both in disease management and in organisation management) should not be discarded.



Paradox 1 : Professionalism vs. Intuition

Who are the leaders?



Intuition

Paradox 2 : Rehabilitation vs. Deterioration

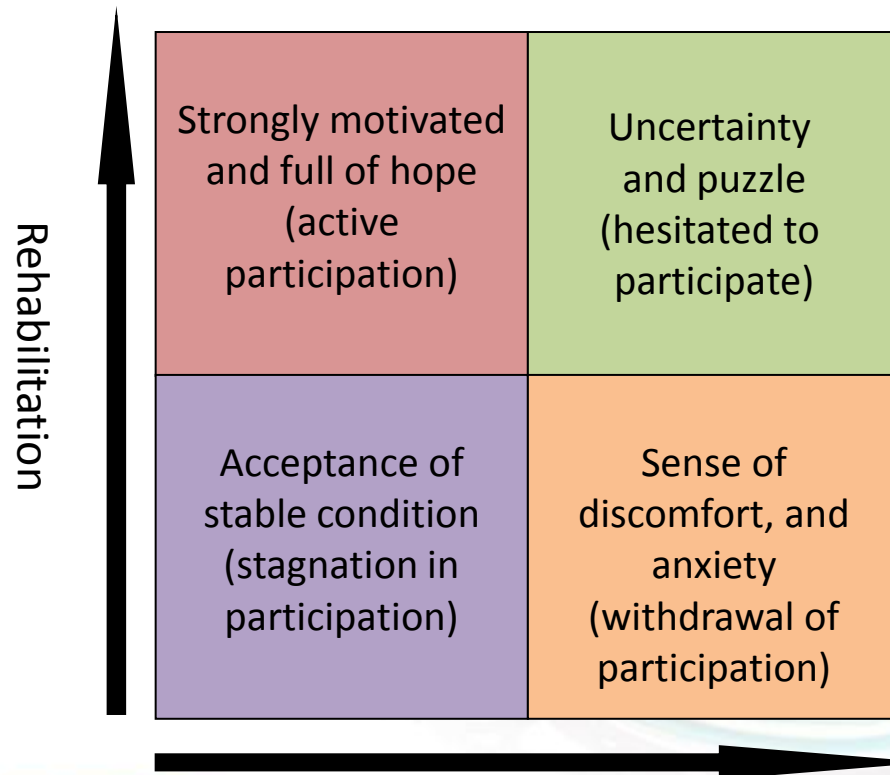
- Patients' condition will deteriorate in time despite their aspiration for rehabilitation. They are even confronted by “death” challenge.
- **As a patient himself**, when the leaders experience health deterioration, there is feeling of disappointment and lost confidence in the organisation . Unstable health condition will also affect their participation in the organisation.



Paradox 2 :

Rehabilitation vs. Deterioration

How's the experience as a patient?



Deterioration

Paradox 3 :

Compliance vs. Confrontation

- Self-help organisation is expected to play the role of advocacy, to advocate for policy change;
- However, this is a big challenge, as :
 - a) much of the energy has been shifted to fulfilling output requirement of different fundings, the major one is from the government;



Paradox 3 :

Compliance vs. Confrontation

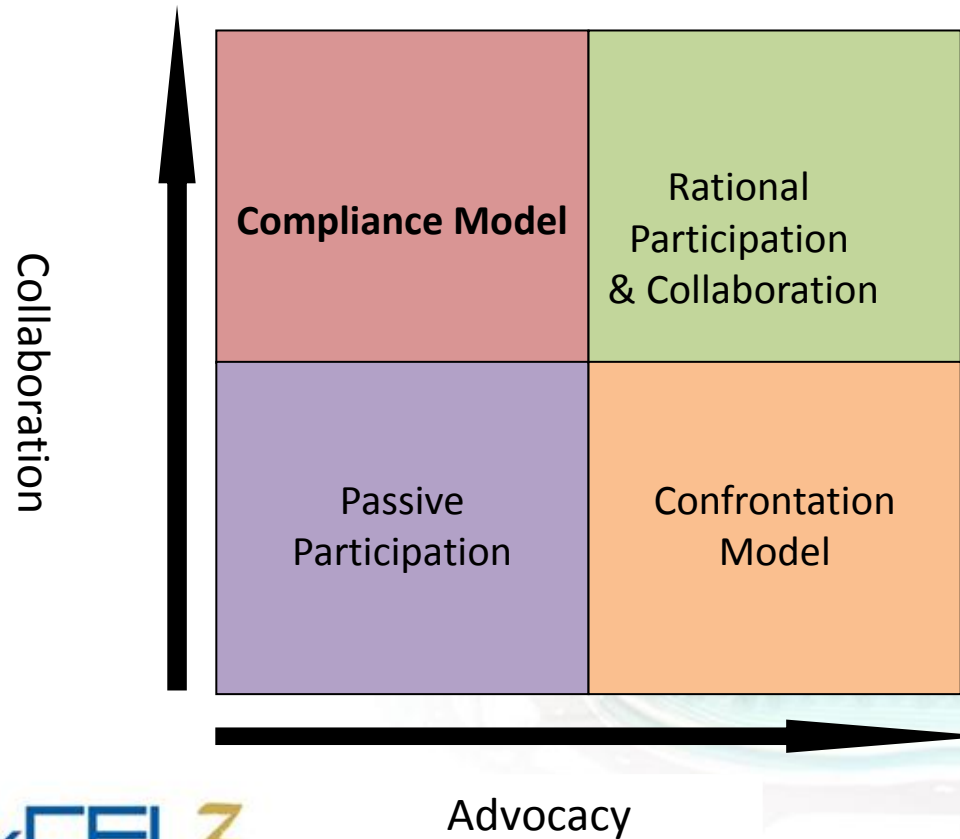
- b) the principle of relational determinism in Chinese culture may lead to preference of harmony rather than confrontation;
- c) Patient leaders may lack of skill in advocacy, e.g. policy analytical skills
 - Instead of advocacy, many self-help organisations moves towards compliance.



Paradox 3 :

Compliance vs. Confrontation

How's the relationship with authority?



Paradox 4 :

Personal Gain vs. Collective Values

- Motives of participation of the leaders :
 - a) Collective values, e.g shared mission of the organisation, common interest of members;
 - b) Personal gain, e.g sense of satisfaction, meaning of life, social network, or even upward mobility in society.



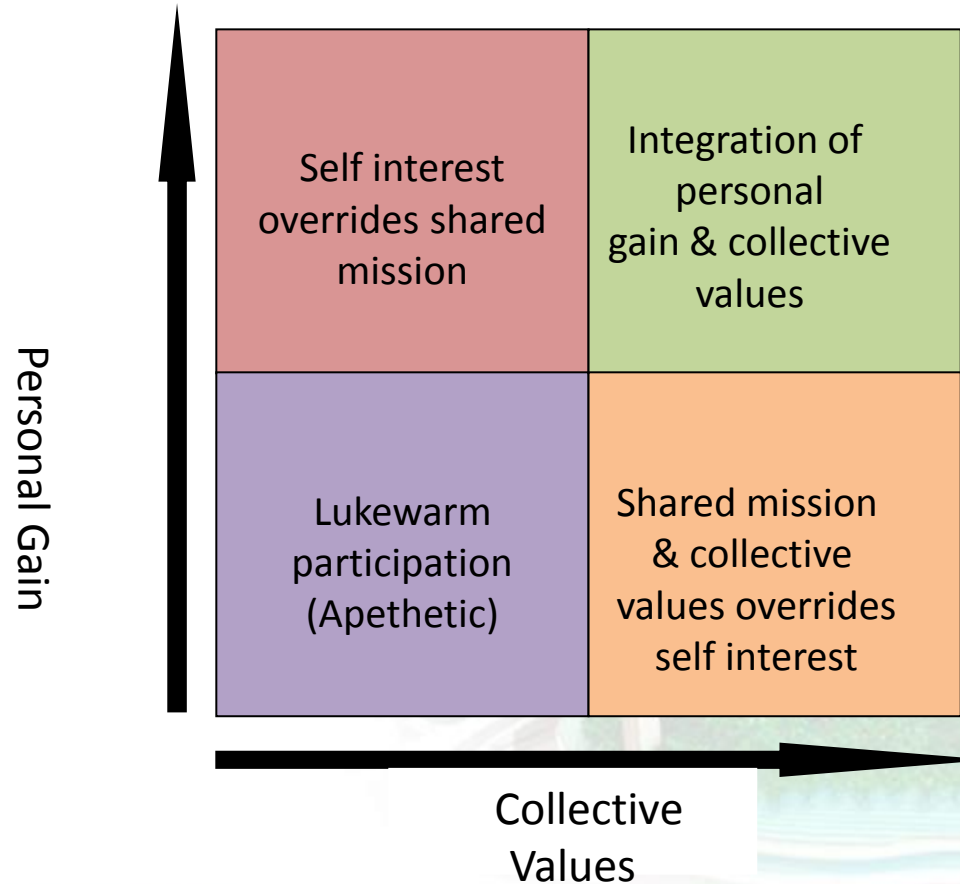
Paradox 4 :

Personal Gain vs. Collective Values

- Integration of the collective values with personal gain may not be easy;
- When personal gains is being ignored, there may be feeling of self-sacrifice; on the other hand, if personal gains dominate, the leader will lose the credibility of being a leader.



Paradox 4 : Personal Gain vs. Collective Values



Paradox 5 :

Leader role vs. Member role

- Leaders are selected among the members. They thus have the dual role of being a leader while also a member;
- This may easily lead to **role confusion**.



Paradox 5 :

Leader role vs. Member role

- They are expected to take up the leader role, but without relevant training, system or manpower support;
- The result may be either **high turnover of leaders** or the same **leader stay on the position for a long time** as it is difficult to get a successor.



Paradox 5 :

Leader role vs. Member role

- Different role perceptions will create different expectations;
- When leaders' self perceived role varies with that perceived by the fellow members, there will be confusion and challenges in leading the organisation.



Paradox 5 : Leader role vs. Member role

Perception of roles
Perceived by Others

		Leader	Member
Self Perceived	Leader	Strong leadership	Difficult to enforce leadership
	Member	Fail to live up to expectation of fellow members	Lack of true leaders to lead the organisation



Conclusion

- Patient self-help organisations have particular status in chronic disease management while their roles cannot be replaced by other professional led organisations;
- By examining the paradoxes of patient participation, we become more aware of the limitations and potentials of development of the self-help organisations.



Conclusion

- Being self-help does not imply withdrawal of support from professional. Without compromising autonomy of the self-help organisations, resources and input from professional, training and educational opportunities should always be available.

