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Humanizing mental health care- Experiences of Peer Support in two different settings in Gujarat after WHO Quality Rights Project

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ABSTRACT

Aims and Objectives: To assess the effects, benefits, acceptance of peer support, attitudes of PSV towards mental illness and patients, recovery of PSVs themselves, challenging aspects of peer support and to explore needs of existing peer support groups.

Methodology: With informed valid consent from participants, a cross sectional study using semi-structured questionnaire was conducted in two settings, GHPU (General Hospital Psychiatry Unit) and HMH (Hospital for Mental Health). Questionnaire taps understanding of recovery, attitudes towards mental illness**;** perceived benefits of peer support to service users, to PSVs themselves and to, organisation; trainings and problems faced as PSV. WHOQOL scale was used to assess quality of life of PSVs before and after working as PSV**.**

Results: PSVs themselves are facing varied mental disorders trying to combat stigma and discrimination. Almost all PSVs stated that trainings of Quality Rights Project were moderately to extremely helpful. 11 PSVs believed that lack of self-discipline and will-power lead to mental illness and there is something that makes it easy to identify mentally ill from normal person. More than half of the PSVs from GHPU feel that peer support improves patients' lifestyle, knowledge, skills and awareness. PSVs themselves improved on knowledge, self-efficacy and communication skills. They perceived that Peer support reduces clinician's time, helps organisation focusing on recovery oriented approach. Paired t tests of WHOQOL scores before and after being PSV revealed significant improvement ($p<0.05$) in all four domains.

Conclusion:. Peer support has great potential to prevent a helper-helpee relationship from being rigid and perpetuating the patient's role**.**

Keywords: Peer support, peer support volunteers, Mental illness, Quality rights

INTRODUCTION

The quality of mental health care and facilities are very important but neglected domain in health services all across the world and especially in India. To improve the quality of mental health care and services, a WHO Quality Rights (QR) Project was implemented in Gujarat. QR Gujarat, a project which started in 2014, aimed to improve quality of care and human rights in mental health services throughout the state with key actions of training staff and service users to promote human rights and fight against stigma associated with mental illness as well as creation of peer support groups to provide people who will take care of the emotional and practical needs of the patients. Among many domains in this project, peer support has gained a major priority after which Peer support volunteers were appointed in some mental health service providing centres. Service users come in contact with PSVs either by 'Maitri' meeting - group run by PSVs for service users or by one to one contact.

What is peer support?

'Peer support is a system of giving and receiving help founded on key principles of respect, shared responsibility and mutual agreement of what is helpful. It is about understanding another's situation empathically through the shared experience of emotional and psychological pain'[1].

Humanizing Mental Health Care

Why the term 'humanizing'? The features of peer support that make it a humanizing force in health care include the amount of time that peer support volunteers (PSV) devote to patients, share experiences of themselves (PSVs) who passed through similar difficult situations of life, and a keen understanding of the patient's culture, community and circumstances.

Peer support harnesses interpersonal relationships to activate intrapersonal change. It embodies widely recognized person-centred principles – patient's choice and empowerment, shared decision making, cultural competency, strengths-based problem-solving, and programming that is adaptive to the needs of patients as they navigate their health and their lives. By supporting patients in ways that matter the most to them, peer support creates a secure environment where patients are at the centre of their health care [2].

Health care professionals should look at patient's willingness to "recover" and not perpetuate the myth that there is a big difference between themselves and patients. Then it becomes a mutual phenomenon where the relationship itself becomes a framework in which both people feel supported in challenging themselves" [3,4].

Can the benefits of peer support only be provided by people who have experiences of mental health difficulties? As Mead said, "When people find others who have had similar challenging experiences, there is almost instant connection (finally someone who really gets it). The real gift lies at the intersection of true reciprocity and the exploration of new meaning and possibility" [5]. Armstrong *et al* reported that service users and PSVs emphasized that the focus of their interactions didn't revolve round their shared psychiatric histories but rather their empathetic relationships with each other [6].

Since the early 1990s, opportunities for the provision of peer support within the mental health system have increased rapidly across the United States as part of the emerging recovery movement [7]. But in India there are very few peer support systems and few studies were done on critical appraisal of peer support. So this study is a holistic approach to assess the effects, benefits, acceptance and challenging aspects of peer support with the aims to find out the different ways in which peer support is described and offered to people with mental health problems – to assess overall recovery of PSVs themselves after working as a PSV and acceptance of PSVs among service users and to explore the needs of existing peer support groups and projects – to increase our understanding of development needs that can support future work programmes to enable peer support projects to increase and flourish.

Materials and Methods

A cross sectional study using quantitative and qualitative questionnaire was conducted in two different settings, 1) General Hospital Psychiatry Unit (GHPU) and 2) Hospital for Mental Health (HMH); running peer support service for last 2 years after Quality Rights Project, Gujarat. The researchers were people with experience of mental health problems (Psychiatrists) with peer support knowledge and research skills.

After ethical approval from respective authorities, "Participant Information Sheets" were given to PSVs individually and Informed Consent Forms were duly filled by participants prior to the study. All PSVs who gave consent were included in this study. Anonymity was explained. Interviews were taken in private room. Data collection was done by survey and questioning method over two months. Data was compared and analysed in two different settings of GHPU & HMH.

Questionnaire for PSV: questionnaire for peer support volunteer was structured after review of literature. It includes qualitative and quantitative information probes describing the benefits of peer support to service users, PSVs and the organisation. It taps socio-demographic profile, mental illness profile, understanding of recovery in mental illness, attitudes towards mental illness and other mentally ill patients, trainings in different areas as part of QR

Volume 2, Issue 5; September-October 2019; Page No.71-80

Project, improvement in themselves after working as PSV and problems faced while working as a PSV.

Scales administered: WHOQOL scale was used to assess quality of life of PSV before and after being PSV.

Results:

Socio-demographic data:

Total of 14 participants working as PSV associated with MH services (4 PSVs in GHPU and 10 PSVs in HMH) participated in the study. Results of two different settings, GHPU and HMH setting of 4 and 10 PSVs respectively are compared.

Out of 14 PSVs, 2 PSV of GHPU and 6 PSV of HMH were males respectively, more females at HMH. All PSVs were educated up to secondary and above, with graduates 2 and 3 from GHPU and HMH respectively. Except one, all others were employed. In HMH, only 20 % were in married state, 60 % were unmarried and 20 % divorced where as in GHPU half of them were married and half of them were divorced. Out of total 14, only 4 (28.6 %) were married.

PSVs had varied mental disorders. Out of 14, 4 had schizophrenia, 8 had mood spectrum disorder and 2 had anxiety spectrum disorder.

To Define Peer support:

In response to a question, 'In your own words, how do you define peer support?' All PSVs from GHPU and HMH tried to define peer support but 3 out of 4 PSVs from GHPU and 6 out of 10 PSVs from HMH defined properly stating that PSVs are patients who voluntarily help other patients during their mental illness. Other 3 PSVs from HMH who defined PSV as only a 'helping person to others' were suffering from schizophrenia whereas one PSV from GHPU who responded same was suffering from anxiety spectrum disorder. All PSVs reported that they work voluntarily and they spend 4 hours per day and 6 days per week for this work.

Trainings as a part of Quality Rights project:

PSVs along with other Mental health professionals, nursing staffs and ward boys successfully completed 4 different trainings regarding Human Rights, Recovery plans, Communication skills, Alternatives to Seclusion & restraint as a part of Quality Rights Project, Gujarat. While comparing both the groups, more number of PSVs from GHPU attended trainings on Human Rights, Communication Skills and Seclusion & restraint whereas all PSVs from HMH and half PSVs from GHPU completed training of Recovery plans in mental illness. As a changing population all were not fully trained but all of them had at least 2-3 trainings. Almost all PSVs who completed training stated, that the trainings were moderately to extremely helpful on 5 point likert scale. Some also helped patients with restraint by sharing their own experiences of restraint.

In response to question asked: "In your own words, what is your understanding of recovery in mental health?"**,** a list of 10 major themes was generated to objectify the subjective answers given by PSVs with the help of description of "recovery" meant in Quality Rights Project. PSVs had different understandings of recovery and all reported 2-3 themes. Most reported themes were of 'one can return to previous life, Improved communication & Behaviour, Improved social life, Improved drug adherence, Decreased symptoms, Regaining Confidence, Explore new opportunities, etc'. As compared to HMH, PSVs from GHPU gave more responses for 'Acceptance- one can lead normal life with mental illness (3 out of 4), New goal and Meaning of life (2 out of 4)', whereas only 3 and 4 out of 10 PSVs from HMH responded for above mentioned two themes respectively.

Attitudes of PSVs towards mental illness and mentally ill patients

Attitude statements were asked in a five point Likert scale. These statements were categorised into 3 domains. 1. Attitudes towards mental illness (statements- 1, 2, 3), 2. Attitudes towards mentally ill person (statements- 4 to 11), 3. Attitudes towards service for mentally ill (statements-12 to 15) (Table 1). All except one statement showed polarization. Ambiguity surfaced on whether responsibility should be given to mentally ill or not, with 8 out of 14 disagreeing, though themselves have taken responsibility of working as PSV.

Although they are working as PSVs, 11 out of 14 believed that 'one of the main causes of mental illness is a lack of self-discipline and will-power' and 9 out of 14 PSVs believed 'there is something about people with mental illness that makes it easy to tell

Volume 2, Issue 5; September-October 2019; Page No.71-80

them from normal people'. This needs to be addressed as these unhelpful attitudes can lead to increase in personal guilt and imposing their attitude on other mentally ill patient can create a hurdle for acceptance of illness, and their efforts can be channelized in wrong direction.

All except one agreed for 'people with mental health problems should have the same rights to a job as anyone else', 'we have a responsibility to provide the best possible care for people with mental illness' and 'mental hospitals are an outdated means of treating people with mental illness'.

In PSVs verbatim, "Mentally ill patients have to be managed without excessive use of restraint. Patients have negative feelings about being restrained. They describe feeling of discomfort, anger, fear and resentment. Everybody wants to go home. Staying for months in a hospital without seeing outside world is very painful."

All agreed that people with mental illness deserve our sympathy and 'we need to adopt a far more tolerant attitude toward people with mental illness in our society'. At the same time 71% (10 out of 14) and 86% (12 out of 14) agreed that people with mental illness are not a burden on society and 'increased spending on mental health services is not a waste of money' respectively. 64% (9 out of 14) agreed that nothing wrong having a mentally ill person in neighbourhood (Table 1).

Perceived Benefits of peer support:

Various benefits to service users, PSVs themselves and organisation were described by PSV. At both places, 10-25 % PSVs feel that service users were benefited by increase in self –esteem, confidence and increased sense of wellbeing, decreased symptoms etc. after meeting the PSVs. More than half of the PSVs from GHPU feel that service users get motivated to implement changes in lifestyle and their knowledge, skills and awareness about mental health increased after contact with PSVs. 71% of PSVs reported that service users can share their problem with them very easily. As all PSVs were trained in recovery plan making at HMH, they all feel that service users get future direction due to recovery plan filling.

Only one PSV reported that service users can accept their state of being mentally ill. Thus, PSVs still need to be sensitized about acceptance of illness is not negative and they can work in this area, which leads to improved drug compliance among service users.

Due to different patient population, knowledge of PSVs and MH services given by PSVs the peer support activities are also different at GHPU and HMH. It also reflects in the 'Maitri' meeting agenda and activities. In HMH there is more in-patient population with chronic illness with more cognitive deficits. So PSVs try to impart some general knowledge (about seasons, festivals, self-care etc.), which can be helpful in new learning and recall. Whereas in GHPU, there is acute, recovering and more heterogeneous population and more than half of the population is nonpsychotic. So activities which are cognitively more challenging and addressing adaptive coping abilities and imparting knowledge about mental illness (importance of treatment, drug compliance, side effects etc.) are done by PSVs at GHPU.

When asked about benefits to PSVs themselves, they answered very confidently with a smiling face, all were happy due to a sense of wellbeing and they were satisfied for helping other patients. According to them during this work they learned a lot about mental illness, improved their self-efficacy, interpersonal communication skills and now they feel that they are important, productive and not just neglected part of society.

Some excerpts of PSVs verbatim –

"Because now I know that, I can be with people who feel exactly the same…

"We help and support each other. We get each other through till the morning, and it's wonderful…

"No pretention, no fake smiles – just honesty and support. It's the most freeing experience I have ever had…

As a part of benefits to organisation, PSVs feel that peer support is associated with better quality of services, it reduces clinician's time, and burden of one to one communication required for improving overall qualities of life and above all it helps the organisation focus on recovery oriented approach.

Quality of life of PSVs before and after working as a PSV: WHOQOL Scale

Volume 2, Issue 5; September-October 2019; Page No.71-80

WHOQOL scale was used to assess quality of life of PSVs before and after working as a PSV. It has been noticed that in all 4 domains transformed scores (0-100) are more in case of after working as a PSV than before being PSV. For all 4 domains, physical health, psychological, social relationship and environment p value is < 0.05 suggestive of statistically significant improvement in quality of life after being PSVs (Table 2).

Challenges of peer support

It is challenging to work in mental health area, and PSVs can also face problems while working in their role. On exploring the area, all PSVs from GHPU were clear about their roles and identified themselves as a service provider and believed that they were accepted in the workplace. Whereas PSVs from HMH face problems in defining and establishing roles and they believed that they were not fully accepted by other professional. As a GHPU has acutely disturbed, moving patient population with different mental illnesses (alcohol use, anxiety spectrum, personality, schizophrenia, mood disorder) as compared to HMH, which has chronic, institutionalised population with severe, chronic disabling mental illnesses (schizophrenia, mood disorder), roles of PSVs are also different in GHPU as compared to HMH. Many problems were reported by PSVs like Personal & professional boundaries, emotional entanglement, Rude and violent behaviour of patient, Insufficient training, etc but one important problem reported from GHPU was interpersonal conflict among PSVs themselves. This could be because of their underlying illness characteristics. Many a times they don't agree with each other and they also have some mood swings which reportedly created difficulties in their work. 7 out of 10 PSVs of HMH, reported that they had insufficient training regarding various topics related to Mental Health.

Discussion:

In international quantitative studies involving PSVs, the impact or outcomes were measured by psychiatric indicators, such as symptom severity and admission rates, or by socio-psychological indicators, such as QOL, empowerment and recovery measurements of service users. Qualitative studies showed enhanced recovery in individuals or groups. As Dixon *et al* noted, peer-support programs often focus on outcomes that have not been traditionally valued or assessed in standard clinical trials [8]. So it is important to place people with personal experience of mental distress at the centre of the report. Four of the studies directly mentioned principles of peer support (Table 3), indicating ways that the experiences or history of mental illness can offer assistance and hope to the people involved in peer support [9-12].

Table 4 shows previous studies[9,12-16] where outcomes, effects and benefits of peer support were elicited. All studies showed positive outcomes, clinical, social as well as economic which is supporting the findings of our study.

Providing Peer Support

Peer-support providers' benefits include self-efficacy resulting from the experience of helping others, increased knowledge about illness and the development of skills through human service work experiences. An opportunity to contribute to the recovery of others also contributes to providers' own recovery [3, 14].

Peer-support providers noted that the benefits of peer support are personal growth that came about from sensitivity to the emotional states of clients, fulfilling commitments, acknowledging, learning from mistakes and perseverance. They also described the development of specific skills and talents, improved communication abilities and increased confidence [14, 18]. Some providers stated that one of the most rewarding aspects was when a peer support recipient said that he or she enjoyed the time spent with the peer support provider. Peer support providers experienced many positive changes in their lives, such as helping themselves to avoid being "withdrawn," "regaining confidence" and gaining "a sense of identity" and the "approval of others" [6]. Many peer-support providers mentioned the benefit of earning money [18]. Although payment status did not affect peer support satisfaction, it was associated with more positive recovery attitudes and engagement in meaningful activities [3].Our study also shows almost similar benefits described by the PSV.

Challenges of Working as a Peer-Support Provider

Many qualitative studies investigated the perceived challenges from the perspectives of the PSV. Most of the challenges were related to "role" and "relationship" issues like role conflict, boundaries, disclosure of peer status, role ambiguity and how

Volume 2, Issue 5; September-October 2019; Page No.71-80

PSVs are treated in the system. When a new type of occupation is established in an existing organization, role ambiguity may be perceived among the newcomers. Carlson *et al.* emphasised that, facilitating discussion about roles with all people involved is a key strategy in providing proper service[3].

Role Conflict

Peer-support providers find the transition from "patient" to "staff/provider" challenging [3, 19]. PSV's difficulties separating their mental health issues from work-related issues were reported not only by peer staff but also by non-peer staff. Non-peer staff may become overly concerned about the peer staff becoming symptomatic, especially if they work at the same facility from which they have received or are currently receiving services [17]. Sometimes PSVs found their role ambiguous, and staff members also were unsure of the role of the PSVs [18] which made PSVs anxious, uncomfortable and led to a lack of support and guidance from supervisors and administrators.

Boundaries

Boundary issues like whether to relate to service users as friends or clients were commonly observed in various studies [18, 19]. A friendship, casual relationships, or relationships involving personal feelings tend to be seen as unprofessional and unethical in traditional service-provider settings [18]. Sometimes peer-support providers have chosen not to share information about clients with mental health professionals for fear of breaching the trust with the client [3].

Disclosure of Peer Status

Peer-support providers who are open and disclose their own experiences are able to build trust with clients and serve as role models for recovery. However, PSVs sometimes felt vulnerable or reluctant to disclose their own experiences or personal information [3, 20].

In our study also PSVs reported of facing problems while working in the particular role. Interpersonal conflict among PSVs, their own mood swings created difficulties in their work.

This study shows that reciprocity and empathetic human relationships are the important aspects of peer support. Service users know what kind of relationship is most effective for them. Most PSVs have experiences of service use, and mental health professionals have much to learn from peer support. So to acknowledge the proper value of peer support, we must extend our view beyond the traditional ways of thinking about help and support.

Strengths of the study: Both qualitative and quantitative survey carried out on PSVs, representing community setting. Though focus was given to qualitative measurements, subjective components were given priority, the subjective answers were objectified with the help of descriptions meant in QR Project, using various common themes selected from the literature and discussion among psychiatrists. WHOQOL, programme satisfaction module were used. Data of two different settings were compared and analysed.

Limitations: It was a cross sectional study with small sample size.

Conclusions: Peer support has great potential to prevent a helper-helpee relationship from being rigid and enhancing the patient's role with self-help and helping others. The outcome is dependent on the individual strengths also, but they can be trained in given areas leading to quality work. Further exploration, awareness and interventions are suggested

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Volume 2, Issue 5; September-October 2019; Page No.71-80

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Volume 2, Issue 5; September-October 2019; Page No.71-80

Tables:

Table 1: Attitudes of PSV towards mental illness and mentally ill patients				
No	Statements	Disagree	Neither agree nor disagree (NAND)	Agree
	attitudes towards mental illness			
1.	One of the main causes of mental illness is a lack of self-discipline and will-power	2	1	11
2.	There is something about people with mental illness that makes it easy to tell them from normal people	2	3	9
3.	Mental illness is an illness like any other	0	1	13
	attitudes towards mentally ill person			
4.	As soon as a person shows signs of mental disturbance, he should be hospitalized	0	2	12
5.	Virtually anyone can become mentally ill	0	1	13
6.	People with mental illness don't deserve our sympathy	14	0	0
7.	People with mental illness are a burden on society	10	2	2
8.	People with mental illness should not be given any responsibility	5	1	8
9.	I would not want to live next door to someone who has been mentally ill	9	2	3
10.	People with mental health problems should have the same rights to a job as anyone else	0	1	13
11.	We need to adopt a far more tolerant attitude toward people with mental illness in our society	0	0	14
	attitudes towards service for mentally ill			
12.	Mental hospitals are an outdated means of treating people with mental illness	1	0	13
13.	We have a responsibility to provide the best possible care for people with mental illness	0	1	13
14.	Increased spending on mental health services is a waste of money	12	2	0
15.	The best therapy for many people with mental illness is to be part of a normal community	3	4	7

Volume 2, Issue 5; September-October 2019; Page No.71-80

Table 2: Quality of life of PSVs before and after working as a PSV: WHOQOL Scale

No.	Domain	Before being PSV mean	Before being PSV SD	After being PSV mean	After being PSV SD	t value	df	Sig.(2 tailed) P value
1.	Physical health	40.786	6.9413	68.071	7.9272	-8.073	13	0.000
2.	Psychological	33.143	7.6345	71.643	14.6424	-7.248	13	0.000
3.	Social relationship	28.071	16.2645	69.571	13.0013	-6.099	13	0.000
4.	Environment	35.929	19.0686	73.857	13.7553	-5.930	13	0.000

Table 3: Principles of peer support

Study	Principles
Adame & Leitner 2008 [9]	The peer support model is rooted in the belief that significant interpersonal relationships and a shared sense of community lay the foundation for the process of healing.
Castelein *et al.* 2008 [10]	Peer support is based on the assumption that people who share similar experiences can offer each other emotional, appraisal, and informational support and hope.
Lucksted *et al.* 2009 [11]	(Peer support is) based on the idea that those who have experienced mental illness can offer help and support to others.
Sells *et al* 2008 [12]	Peer staff were individuals who had chosen to publicly disclose their history of mental illness and subsequent recovery, with the intention of using these experiences in concert with their clinical talents and skills to assist clients who were currently dealing with active psychiatric problems.

Table 4: Outcomes, Effects and Benefits of Peer Support

Study	Program Description	Outcome
Castelein *et al* 2008 [9]	A closed peer-support group discussing daily life experiences. The group has 16 90-minute sessions biweekly over 8 months.	Peer support groups had a positive effect on social network and social support compared with the control condition.
Sells *et al* 2008; 2006 [12, 13]	Intensive case-management teams that included peer providers.	Participants who received peer-based services felt that their providers communicated in ways that were more validating and reported more positive provider relationship qualities compared

Volume 2, Issue 5; September-October 2019; Page No.71-80

		with participants in the control condition
Lawn *et al* 2008 [14]	Early discharge and hospital avoidance support program provided by peers.	300 bed days and costs were saved by the peer service.
Yanos *et al* 2001 [15]	Programs that are staffed and operated completely by self-described mental health consumers provide services such as self-help, activity groups, and drop-in groups.	Involvement in self-help services was associated with better community adjustment, the use of more coping strategies, and a greater proportion of problem-centred coping strategies
Corrigan 2006 [16]	Consumer-operated services	Participation in peer support was positively correlated with recovery or empowerment factors.

Volume 2, Issue 5; September-October 2019; Page No.71-80