



## FEATURE

## ESSAY

## Communitisation of healthcare: peer support groups for chronic disease care in rural India

Such groups can help patients find support, adhere to treatment, and advocate for their needs collectively, say **Yogesh Jain** and **Priyank Jain**, describing their impact in a resource poor setting

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Historically, health systems evolved to tackle the most prevalent illnesses—primarily acute infections and injuries. The management of chronic diseases requires the sustained motivation of patients to engage in long term adherence and periodic review of the treatment plan. Even in developed countries, long term adherence rates are about 50%—in developing countries the rates are much lower.<sup>1</sup> Given this, the assumed primacy of doctors and hospitals as providers of care is increasingly being challenged, and recognition is increasing that health outcomes are “co-produced” by healthcare systems and patients.<sup>2</sup>

Peer support is support from people who have the same health condition as the patients they help—they experience the same challenges of living with the same chronic condition. A review of 1000 studies from countries of the Organisation for Economic Co-operation and Development noted that peer support groups improve patient experience, psychological outcomes, behaviour, health outcomes, and service use among people with long term physical and mental health conditions.<sup>3</sup> It describes many effective models of peer support: face-to-face or telephone based; one-to-one or groups of 10 or more; run by trained peers or healthcare professionals. All these models require investment in organisation of the peer networks, and most of the research is from North America.

In poorer countries, peer support groups have been used for mental illness<sup>4</sup> and HIV<sup>5</sup> but with relatively little research on benefits or about applicability to other chronic diseases.<sup>6,7</sup> Patients in poorer settings are even more vulnerable because they also lack access to healthcare facilities, which can be a further demotivator to the long term engagement needed for optimal health outcomes.

In this essay we describe our experience of using on-to-face (?OK?) peer support groups for chronic disease management facilitated by community health workers in rural central India.

### Patients offer solutions and support each other

Chhattisgarh state is home to many of the poorest people in India, with over 40% of the population living below the poverty line<sup>8</sup> and ranking lowest in human development index among the Indian provinces.<sup>9</sup> Eighty per cent of the population live in rural areas, and almost 30% are tribal. State expenditure on health was 1200 rupees (£13.97; €15.78; \$18.92) per capita in 2016–17.<sup>10</sup>

Jan Swasthya Sahyog (JSS) is a non-profit healthcare organisation that has provided comprehensive healthcare in rural Chhattisgarh since 1999.<sup>11</sup> We run a referral hospital and a community health programme that sends trained community health workers to 70 forest fringe villages. The cost of care is kept low—a month's refill and monitoring investigations cost a maximum of 200 rupees—and all patients are given care regardless of ability to pay. Community health workers are chosen from the villages in which they work and live. Doctors and other healthcare providers visit three remote clinics that increase accessibility for patients.

Despite our attempts to provide healthcare aligned with the contextual needs of these communities, the health behaviour and outcomes of patients with chronic diseases remained dismal even after a decade. Rates of adherence to treatment were 20–40%, and we witnessed avoidable morbidity and mortality attributable to treatable diseases like epilepsy and sickle cell disease. We surmised that suboptimal health behaviours were a result of knowledge gap and decided to offer educational intervention.

So, in early 2013, one-to-one teaching sessions were initiated with patients who accessed the outreach clinics for follow-up care of sickle cell disease. Soon this grew into group sessions

led by trained community health workers to educate many patients simultaneously. Then we observed something interesting: patients started offering solutions and support to each other. The group had transformed from an informational session to a knowledge sharing, community building forum. Our first peer support group thus started in February 2013 with 11 patients with sickle cell disease.

## More groups for other diseases

Encouraged by the sickle cell disease group, we started other disease based groups. Whenever six or more patients from nearby villages with the same disease were willing to participate, a community health worker would facilitate formation of a group. Between February and September 2013, groups had formed for sickle cell disease, epilepsy, diabetes, major psychiatric illnesses, alcohol dependence, airborne contact dermatitis, hypertension, chronic arthritides, and asthma and chronic lung diseases.

Health workers kept written records of discussions and questions from meetings, and met monthly to share experiences and for training and quality improvement. This consolidated best practice and standardised operating processes.

The groups met once a month, with the venue rotating among members' villages to encourage equity in distances travelled. Meetings started with members sharing highs and lows since their last meeting and questions about the illness and treatment. Then health workers shared new knowledge and corrected misunderstandings. In many groups the health worker also dispensed drugs for stable patients, following pre-specified algorithms. Physical activity was woven into sessions as games or exercise. Each group got a small allowance for tea and snacks of 250 rupees. Each group selected a chairperson and secretary among the participants who organised the meeting and agenda.

With more autonomy and shared identity, the groups started organising themselves. Many identified specific agendas relevant to their disease and undertook collective action. For example, the alcohol support group took on the task of manufacturing the ready-to-eat food that is used by JSS for nutritional supplementation in its programmes as an income generating activity. The epilepsy group recruited patients who had dropped out of care. The hypertension group lobbied shopkeepers not to sell high salt snacks.<sup>12</sup> The sickle cell disease group spawned new groups in other villages and lobbied the government for better access to drugs, facilities, and disability benefits.<sup>13</sup> In this exciting phase we saw empowerment and collective action by hitherto disenfranchised people.

In 2015 in *The BMJ*, Mulley et al described "high integrity health systems," dedicated to providing services that people need and want, and that put the interests of patients and the public above those of all other stakeholders.<sup>14</sup> Learning from populations to deliver value to individuals is the central strategic intent of such a system achieved through engagement of patients. The peer support groups at JSS reflect the design principles identified (↓).<sup>15</sup>

## Results

As of October 2017, 49 groups represented 10 chronic diseases, with 693 total participants. Drug refill records show that continued attendance in August and September 2017 was over 90%. Twelve health workers manage four to five groups each.

As of October 2017, more than 90% of the groups remain active. Health behaviour such as patients' drug adherence has improved to 76%-94%, compared with 20%-44% before the groups started

(↓). The adherence rate for antiepileptic drugs, for example, used to be 40%—even though the drugs were provided free of charge. Currently, the compliance rate exceeds 90%; greater adherence has resulted from peer groups being able to support and motivate members. Peer support promotes self care and may improve disease outcomes. For diabetes, for example, self care includes regular washing of feet and inspecting them for ulcers or injuries.

Group meetings are intended to be unthreatening, to foster mutual learning among members and health workers. An intangible outcome of this is a sense of belonging and more self esteem. We believe that the social connectedness that emerges from enduring adversity together is key to focusing on recovery—and to be able to support others in their recovery.

The health programme at JSS has witnessed a paradigm shift, where people with illnesses are transformed from passive recipients of treatment to active agents in healthcare. From an individual's viewpoint, being part of a peer support group is a process of accumulating individual strengths to give a collective voice to the concerns and needs of individual patients. As well as advocacy we have seen positive changes at JSS: fewer outpatient visits for routine follow-up of stable patients have improved operational efficiency, and there has been more recognition by healthcare workers of the challenges that patients face in adherence and in sharing responsibility for finding solutions.

## Communitisation of healthcare

The present public healthcare model in rural India has largely failed to tackle either the diagnosis or continued treatment of chronic diseases. The for-profit private sector is either not there, is not interested in screening for these illnesses, or does not have structures to ensure drug adherence.<sup>16</sup> Peer support groups represent the "communitisation" of healthcare, combining access to government funds and expertise with the social capital of healthcare users to improve local healthcare delivery. Harnessing the intrinsic strength in grassroots communities requires new governance structures, such as giving groups space to conduct meetings and recognition of their demands. This is especially relevant in rural India, where options to streamline the government system have failed and privatisation is seen as unviable.<sup>16</sup>

Some diseases come with social stigma, and patients risk marginalisation. Patients with epilepsy were apprehensive about seeking care and continuing treatment, for example. We were unsure if they would participate with disease specific groups. However, groups of patients with epilepsy were able to overcome this barrier and recruit new patients from the community for diagnosis and treatment.

Face-to-face groups are not feasible for all chronic diseases. We had two groups that did not last. One was for patients with rheumatoid arthritis, where impaired mobility of patients prevented participation in face-to-face meetings. The other was for parents of blind children. The low prevalence of this condition meant groups formed over large distances. Other models, such as one-to-one and teleconference, may be successful in these situations but are not feasible in poorer communities.

Effective peer support groups require investment in organisation and in the training of facilitators. Evidence indicates that patient groups are most effective for improving health outcomes when they are delivered in person in groups of more than 10, have trained facilitators, include specified activities (such as exercise

or a choir), and focus on education, social support, and physical support.<sup>3</sup> Our experience aligns with these findings.

Peer support can be a valuable coping tool for patients and care givers for many chronic problems, including HIV,<sup>5</sup> type 1 diabetes,<sup>17</sup> burns,<sup>18</sup> stroke care givers,<sup>7</sup> cancer,<sup>19</sup> and dementia.<sup>20</sup>

It can complement the healthcare system by engaging patients and their communities in producing healthy outcomes; however, it cannot replace a working healthcare system.

Further research is needed to consider any impact on health outcomes; other ways to create peer support groups for patients with limited mobility; the feasibility of peer support groups in communities without a functioning healthcare system to provide medical care; and how advocacy by peer support groups can shape healthcare systems.

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## Tables

**Table 1 | Peer support groups as examples of high integrity health systems**

Design principles for high integrity health systems	Peer support groups at Jan Swasthya Sahyog
<p>Continuous learning from and with populations: Is the expertise of patients, family, and carers reflected in learning collaborations? Is there a means to identify what is not working for patients and to stop ineffective practice?</p>	<p>Individual members share their experiences with the health workers and with each other, facilitating mutual learning</p>
<p><b>Co-production by teams of what is valued by people:</b> Are clinicians supported to ensure patients understand the benefits, harms, and uncertainties of available interventions, and to find out what matters most to patients?</p>	<p>Health workers gather once a month for ongoing technical training and sharing best practice for peer support groups</p>
<p><b>Access to information, support, and integrated services:</b> Are service users given ready access to consistent information and support to assess their need for services and their role in managing them?</p>	<p>Health workers share new information and correct misunderstandings in meetings. In many groups they also dispense drugs for stable patients, following pre-specified algorithms</p>
<p><b>Supporting the personal agency of all people served:</b> Do care models support enhancement of motivation, confidence, and capabilities of all the people they serve—without exception—as well as those who serve?</p>	<p>Peer support groups have been successful in setting the agenda for advocacy and self help based on their felt needs. Health workers improve their technical knowledge and facilitation skills</p>
<p><b>Mutual accountability among all stakeholders:</b> Do care models tackle the interdependencies among people with health concerns, the professionals and staff who serve them, and the policy makers and leaders responsible for governance and stewardship of resources in the healthcare economy?</p>	<p>Federations of peer support groups have been effective in outreach to patients and lobbying local government for appropriate disease care in the community</p>

Table 2| Adherence to treatment after joining peer support groups

Disease or illness	Number of groups	Total number of patients	Drug compliance* in Jan 2013 (before groups)	Drug compliance in Jan 2017 (with groups)
Alcohol detoxification†	12	198	20%	76%
Epilepsy	4	57	32%	94%
Sickle cell disease	3	70	30%	88%
Type 1 diabetes	2	35	<25%	83%
Type 2 diabetes	2	44	40%	90%
Common mental disorders	6	84	20%	88%
Major mental disorders	3	48	28%	92%
Hypertension	8	196	44%	92%
Asthma	2	28	40%	90%
Airborne contact dermatitis caused by pollen of <i>Parthenium</i>	2	40	20%	86%

All groups formed between February and September 2013, some groups numbers increased in 2014. All members were part of these groups for at least two years. All patients with these conditions were group members, except for hypertension (about 50%) and type 2 diabetes (64%). \* >80% drugs consumed a month for >6 months. †Complete abstinence for six months.