

## USING FOCUS GROUPS IN COMMUNITY BASED REHABILITATION

Manoj Sharma\*

### ABSTRACT

*The purpose of this study was to examine the method of focus group in community-based rehabilitation. An intensive ten year search of Medline database, revealed twenty six articles that had used focus group as primary or secondary method and that pertained to rehabilitation in community settings. The articles were categorized into five categories based on how focus group was used, namely, needs assessment, evaluation, developing an instrument, developing a conceptual framework, and as an intervention. Most of the studies were done for needs assessment (n=19) with very few in the other four areas. Focus groups are an invaluable method that has been underutilised in CBR. These can aid the research enquiry or in participatory paradigm, these can be utilised as a means of community empowerment.*

### INTRODUCTION

Since 1976, community-based rehabilitation (CBR) strategy has been the chosen approach by the World Health Organisation (WHO), for serving the needs of persons with disabilities in developing countries (1). Over the last two decades, this CBR approach has been applied in more than thirty countries through governmental and non-governmental initiatives (2). The model which was initially perceived as an extension of the medical model linked with the infrastructure of primary health care (PHC), has evolved into a more comprehensive social model, that relies more on voluntary community participation and resources (3). The primary tenet of CBR is to provide primary care and rehabilitative assistance to persons with disabilities, by using human and other resources already available in their communities. The five basic principles of CBR strategy include:

- Utilisation of available resources in the community.
- Transfer of knowledge about disabilities and skills in rehabilitation, to people with disabilities, families and communities.
- Community involvement in planning, decision making, and evaluation.
- Utilisation and strengthening of referral services at district, provincial, and national levels that are able to perform skilled assessments with increasing sophistication, make rehabilitation plans, participate in training, and supervision.
- Utilisation of a co-ordinated, multisectoral approach.

In community-based work and research, a method that is commonly employed is focus group discussion. The purpose of this article is to examine the extent of use of focus groups in community-based rehabilitation and discuss its potential applications. The article begins by discussing the technique of focus group. Next, the methodology for locating published works utilizing focus group in CBR is presented. Then, the published literature with regard to focus groups in CBR is categorised and summarised. Finally, the implications of the findings and applications in CBR are discussed.

Focus groups owe their origin to the field of marketing (4). The marketing researchers primarily use this method for testing the negative and positive perceptions of target audience, about various new commodities or potential ideas. Focus groups are indispensable for community entry to gain early impressions (5). Focus groups are especially important in determining which populations to target. Focus groups are also used in developing and modifying psychometric instruments. These are also being used in evaluation of programmes including critiquing educational materials such as pamphlets, posters, public service announcements, and so on. Focus groups are also helpful in triangulating results from quantitative data.

The focus group method entails developing a detailed protocol (5). In developing the protocol, first the research topic is decided. The time planned for conducting a focus group session is between one and two hours. The guidelines start with directions for recruitment of the focus group members (8 to 12 persons with a minimum of 4 groups for each topic). It is important to keep the recruitment instructions simple and brief, and giving participants some incentive or reward, for participation. The first decision in recruitment is whether to keep only gender or combine the two sexes. If possibility of any potential threat to openness is perceived, the focus group must be restricted to only one sex. The next decision is regarding the socio-economic status of participants. Once again, efforts must be made to keep homogeneity. Similarly, efforts must be made to have homogeneity with regard to race, ethnicity, national origin, and spoken language. Finally, to ensure that discussion is more honest, efforts need to be made, such that participants do not know each other.

The focus group protocol includes direction for conducting the discussion. Each discussion starts with introductory comments from the moderator thanking the participants, explaining the process, making clear that everyone's input is important and introducing rules such as one person to speak at one time, and that people should speak what they think not what someone else wants to hear. It is very important to instruct the participants that there are no correct or incorrect responses, but the purpose is mainly to elicit opinions. An opportunity must be given for the participants to briefly introduce themselves. The questions that follow must be open-ended, with an aim to stimulate the discussion and not tallying responses. The protocol must have examples of questions that will avoid a yes/no response.

In conducting the focus group one must choose a convenient location, and try to create as relaxed and familiar an atmosphere as possible for participants. Nametags with first name only (to allow confidentiality) must be provided. Furthermore, for topics related to health education, one must have a content expert available, who can provide correct misinformation at the end of the focus group discussion. While conducting focus groups, it is also advantageous to have an observer who should note interactions, body language, and record content exchanges. In conducting focus group discussions, having an experienced and competent moderator is an important prerequisite.

The focus group discussion must be tape recorded after consent from the participants. It is also helpful, if the moderator can use flip charts to document the data and seek clarity from participants. In analysing the data the analyst must first listen to the whole tape recording and its transcript, to get an overall impression. Then tabulate and organise discussion group findings and pertinent quotations. Emphasis must be made to evaluate differences between the thoughts, beliefs, and emotions of different people. The analyst must pay special attention to participants' hesitations, silences, and emphases, as well as actual words used.

The chief advantage of focus group discussion, is that these are inexpensive and relatively quick means of collecting data. Focus groups are an effective means to reduce distance between the target population and facilitators. In conducting focus groups, probing an issue is possible, which provides richer contextual information. Often, brainstorming and interaction may result in insights. Another advantage of focus groups, is that these allow expression of honest and spontaneous responses, rather than intellectual opinions.

One of the disadvantages of focus groups is that the group members may not be representative of the target audience. Often, when the moderator is not experienced, the moderator and dominant participants influence the responses. On sensitive topics, group members may be inhibited from discussing private topics in public. A major disadvantage, is that the nature of data precludes drawing firm conclusions. Finally, focus group data is easily subject to misuse, through absence of the required moderating skills and through misinterpretation of the data.

## **METHODOLOGY**

A search of the database Medline using the words "focus group", revealed 5,105 articles. Addition of the word "rehabilitation", resulted in 333 articles. The articles were further narrowed down by hand search to select CBR studies that met the following criteria:

- used focus group as a primary or secondary method.
- based in community setting.
- pertained to rehabilitation.
- published between 1994 and July 2004.

Excluded from the analysis were articles that were: (1) review articles; (2) were primarily based in institutional/hospital setting; (3) did not explicitly deal with one or more aspects of rehabilitation; and (4) were older than 1993.

A total of twenty six studies met the criteria that have been summarised in the results section. These studies have been categorised into following categories:

- Focus group used for needs assessment
- Focus group used for evaluation
- Focus group used for instrument development
- Focus group used to develop conceptual framework for research/evaluation
- Focus group used for intervention

## **RESULTS**

### **Focus group used for needs assessment (n=19)**

A Swedish study for needs assessment of women on sickness leave, was conducted to ascertain how they perceived and described the possibilities and barriers for resuming work (6). The method entailed conducting five focus groups with a total of twenty subjects. In data analysis the researchers were able to identify three themes.

Another qualitative needs assessment study was done in Northeastern China, to discern the perception of quality of life in adults with spinal cord injury (7). The method comprised of conducting six focus groups with 40 subjects. In data analysis, the researchers were able to identify 18 components that they could classify into five domains.

Interactions with rehabilitation workers sometimes influence the reasons for resuming work after a prolonged illness. A Swedish study utilised five focus group discussions among persons who had been absent from work with back, neck, or shoulder injuries, to explore the influence of positive experiences from rehabilitation workers (8). In data analysis, the researchers were able to identify two categories of positive experiences.

In another needs assessment study from Taiwan, six focus groups with forty-four elderly men and women were used to discern quality of life issues (9). The data analysis identified six dimensions of quality of life.

Another study done in Northern Ireland to document experiences of caregivers of people with multiple sclerosis, utilised focus group discussion with sixteen subjects (10). The data analysis was able to identify four phases that caregivers experienced.

Another needs assessment study with 14 Australian Vietnam Veterans diagnosed with post traumatic stress disorder utilised three focus groups (11). The purpose of the study was to prospectively gather perceptions, attitudes, and opinions regarding an exercise programme.

The data analysis revealed three main themes.

A British needs assessment study used focus groups to explore the perceptions and potential role of community nurses in rehabilitation work (12). The findings were able to identify the role community nurses could play and various challenges that confronted this performance.

Another Canadian needs assessment study used focus groups to explore the perceptions of injured workers toward return to work programmes (13). The data analysis was able to identify several common themes.

Another needs assessment study done in Hong Kong aimed at identifying the characteristics of quality of life among elderly stroke survivors using focus groups (14). Results were triangulated by review of literature and data gathered from World Health Organisation Quality of Life Scale. A total of 36 components were identified.

In order to identify barriers to wellness activities experienced by Canadian women with physical disabilities, a needs assessment study was done, that utilised focus group discussions (15). The study was able to identify internal and structural barriers.

A needs assessment study done in Uganda, aimed at identifying factors that influence the use of rehabilitation services at an urban hospital (16). Key informant interviews and focus groups were used to obtain data from injured persons based in the community. Several barriers to service utilisation were identified.

Another needs assessment study done in an urban slum in India, was done to collect data about knowledge, skills, and attitudes regarding disability, feeding and nutrition practices among children with disabilities (17). The authors write that, "The focus-group findings enabled a broader understanding of attitudes towards disability within this population, which can have an impact on the care of the child."

A British needs assessment study aimed at identifying the perceptions of primary health care workers, regarding persons with learning disabilities and the extent to which they are meeting their needs (18). Data was obtained through focus group discussions and semi structured interviews. The study identified several barriers and attitudinal deficiencies.

Another needs assessment study aimed at assessing sexual knowledge, attitudes, and practices of persons with spinal cord injury (19). Eight focus groups with twenty eight participants were conducted. Several issues were identified.

Another needs assessment study done in Taiwan used focus group discussion to investigate perceptions of health-promoting self-care in community-based older adults (20). Three focus groups with 21 participants were organised. Five major themes were identified.

Another needs assessment study was done to determine the impact of stroke and to identify the needs of survivors (21). Focus groups were conducted with stroke survivors, care givers, and other key informants. Several themes were identified.

Another needs assessment study was done in Hong Kong to understand the perceptions of quality of life by elderly (22). Focus group discussions with seven elderly and six healthy elderly were conducted. Several components of quality of living were identified.

Another needs assessment study to explore the experiences, perceptions, and needs of youth with physical disabilities, in transition from adolescence to adulthood utilised focus group interviews (23). Themes regarding context, the transition process, needs, and services were identified.

Another Canadian needs assessment study was done to describe feelings of women with spinal cord injury (24). Focus group discussions with ten participants and key informant interviews with 19 participants, were used. Several feelings were identified.

#### **Focus group used for evaluation (n=3)**

A videoconference linked intervention for community-based stroke rehabilitation was conducted in Hong Kong (25). In order to evaluate the one of the qualitative tools utilized in conjunction with quantitative methods was a focus group with nineteen subjects.

A participatory evaluation of a CBR programme done in Vietnam, utilised focus groups along with semi-structured interviews to collect data from village, commune, district, provincial, and central levels (26). Data was examined against the five principles of the WHO model, namely, available resource utilisation, knowledge transfer, community participation, referral services strengthening and multisectoral coordination. The strengths, weaknesses, opportunities, and threats across all levels were identified.

A community based rehabilitation programme was evaluated in the Philippines using focus groups, record review, and in-depth personal interviews (27). The evaluation was able to identify strengths and weaknesses of the CBR programme.

#### **Focus group used for instrument development (n=1)**

A Canadian study used four focus groups to develop a questionnaire for persons with multiple sclerosis to gauge their needs (28). Ten persons with multiple sclerosis and five significant others participated in the focus group discussion. Seven themes were identified that became categories for instrument development. The phraseology of the participants served in shaping the items.

#### **Focus group used to develop conceptual framework for research/evaluation (n=1)**

In order to develop a conceptual framework of salient areas for evaluation of rehabilitation outcomes in older people, focus group discussions with eight experts were used along with

semi structured interviews and literature review (29). The data analysis revealed four domains for conducting evaluations.

**Focus group used for intervention (n=2)**

A South African participatory study done with spinal cord injury self-help group, aimed at enhancing empowerment (30). Group management and decision making were assumed by the self help group members. The group was able to generate opportunities for empowerment and self reliance among people with disability.

A Chinese study aimed at enhancing agreement between community members and health professionals, on functional needs of patients with different chronic diseases (31). Focus groups and questionnaires were used to collect data and enhance agreement between community members and health professionals.

**DISCUSSION**

The purpose of this study was to reconsider the method of focus group in community-based rehabilitation. An intensive search of Medline database revealed twenty six published articles in CBR, that used focus groups in the recent ten-year period. The number of published studies in CBR, that have used focus groups is very few, compared to the use of this methodology in the larger field of health science. Within the field of CBR, most of the studies have used focus groups for needs assessment

Very few studies have used focus groups as a tool for making change or as an intervention itself. In participatory paradigm, focus groups offer tremendous scope for enriching the skills of the participants and must be utilised more by researchers. In this approach, the facilitation of the focus group discussion, after due training of the participants, is assumed by the participants themselves. Likewise, use of focus group for instrument development or developing conceptual framework has also been inadequately utilised. Only three published studies have used focus groups in evaluation of CBR. Focus groups are most practical and invaluable tools for rapid data gathering in evaluations, and must be used more often.

There are several limitations of the present analyses. Only one database namely Medline was chosen for retrieving the articles. As a consequence, several studies published in journals that are not indexed in Medline, were omitted. The search period included a time frame of ten years starting from 1994. Community based rehabilitation as a strategy, is more than two decades old and as a result, once again, several articles from the previous decade have been lost in this analysis. Classically, community-based rehabilitation refers to projects and programmes in developing countries. However, in the present, analysis studies from developed countries have also been included, provided these studies were

related to community settings. This has increased the number of studies and may have inflated the actual number of true CBR studies.

On the whole, it is important to note that focus groups are an invaluable method that has been underutilised in CBR. More use of focus groups either by researchers to aid in research enquiry, or in participatory paradigm, as a means of community empowerment must be done.

\*Associate Professor, Health Promotion and Education  
University of Cincinnati  
526 Teachers College, P.O Box 210002  
Cincinnati, OH 45221-0002  
Phone: 513-556-3878. Fax: 513-556-3898  
manoj.sharma@uc.edu

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