

A CONSUMER PERSPECTIVE
ON QUALITY CARE
THE RESIDENTS' POINT OF VIEW

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NATIONAL CITIZENS' COALITION FOR NURSING HOME REFORM
1424 16th Street, N.W. Washington, DC 20036
202-332-2275

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Executive Summary

The purposes of this study are to collect and document information about quality care and life in nursing homes and to promote use of this information for identifying quality of care and quality of life factors when surveying nursing homes.

What is quality care? How can it be defined in a way that it can be identified and measured? To find the answers to these questions, discussion sessions were held with 457 nursing home residents in 15 different cities. A broad range of persons from 105 nursing homes throughout the country participated in discussions.

The first phase, or round, of this study was based on open ended discussion groups where residents were asked to identify quality markers for care and for life in a nursing home - both their own and an ideal home. The responses given by the residents in the Round One semi-structured discussions were analyzed to determine the predominant nursing home quality care components. The quality care components that were identified most often by residents were used to focus questions for Rounds Two and Three.

The questions used were designed to elicit further information about areas many residents find are important in their care and life in a nursing home. In addition, we wanted to collect two sets of information from the consumers' viewpoint: 1) What kinds of rules could result in good quality care, and 2) What inspectors should look for to know if quality care is being provided. Finally, we wanted to know from the participating residents what actions might bring about quality care.

A panel of research advisors helped develop guidelines for selection of residents, structure of discussions, and recording of sessions. Local coordinators, trained in the research project's guidelines, facilitated the discussions and recorded residents' responses. Responses to Rounds Two and Three were analyzed through content analysis. Quality care items were grouped and ranked in order of the frequency with which they were mentioned in discussions. A summary of residents' responses is provided on pages I -12-17.

An analysis and summary of these responses was presented at a National Symposium on Quality Care held in Clearwater Beach, Florida, February 8-10, 1985. Residents representing the discussion sites joined health care professionals, educators, researchers, service providers, government officials and consumer advocates to discuss the study findings and consider strategies for implementation of residents' views.

The Symposium brought to life the* basic tenets of the project, the possibility and the value of resident participation. Residents and long term care professionals engaged in an historic exchange which added meaning and dimension to the summary of residents' discussions. A summary of the Symposium highlights is presented on pages I - 18-19.

SUMMARY AND HIGHLIGHTS OF RESIDENTS' RESPONSES

(Discussion Sessions: Rounds Two and Three)

STAFF

Residents in this study stress the great importance of staff, equating good staff with feeling content and happy. Residents most often speak of the "help" they receive from staff as the meaning to them of "good" staff.

Residents discussed the meaning of good staff in two contexts: 1) what staff could do or be in order to make life better for them, and 2) the impact on residents' lives of good staff care. Having sufficient numbers of staff, positive staff attitudes and good staff relationships with residents were the issues residents raised most often in the discussions.

Residents in this study emphasized the importance of qualified staff, well trained, skilled and knowledgeable. They also want staff to be well supervised.

When residents were asked what could be done to improve the quality of staff, they focused on the need for more staff, more supervision, orientation and training of staff. They felt that staff need to develop positive attitudes toward residents. Residents also talked about the importance of finding and hiring qualified staff for a nursing home. They see increased pay as one way to achieve this.

Responses- fell into two categories when residents were asked, "What would improve the quality of staff in nursing homes?" Residents address how to improve quality through modifying staff performance and staff attitudes.

Discussing training, residents in the study most frequently identified the need for staff to receive training to perform specific care tasks. The residents also cited the importance for staff to learn to perform personal service tasks and to use basic nursing skills better. In keeping with a theme that runs throughout the study, residents underscored the need for staff training in the areas of human relations and psychological skills. They felt that staff should learn to communicate better with residents.

A wide range of training modalities are identified by residents as important training areas. These touch on almost all aspects of care. They have done this from their perspective, but also with a high degree of understanding of training issues and methods.

When asked what would make people want to work in nursing homes, residents agreed that wanting to care for and help people was the primary motivation. Residents discussed how better pay and career development possibilities would make more people want to work in nursing homes.

ACTIVITIES

Residents in this study say they want lots of activities, more than what they now have. They want variety to meet their wide range of interests and needs. The responses given by residents reflect personal preferences and represent their diverse individual life experiences and capabilities. This includes the less able residents.

Social activities headed the list, followed by games and activities outside the home. All groups of residents indicated they want to take part in community activities and events. And they would like people from the community to participate in and to provide activities in the home. Residents discussed the need for activities during the evenings and on weekends.

Residents report that they want to make their own choices about what activities to attend, when, and the degree of participation.

Residents recognize that a good activities director is basic to having good activities, and he or she should be understanding, but above all active.

In this study, residents say they would like staff members to participate with them in activities in or out of the home.

Residents in this study emphasize the importance of a diversified program responsive to resident input. They want choice. Residents want to be active seven days a week. They say that participation with the community inside and outside the home is as essential for a good activities program as is a good, active and compassionate activities director.

FOOD AND FOOD SERVICE

Residents in the discussion groups say they want variety in food, a wide range of fresh, well prepared and tasty foods to choose from. They want foods that provide for ethnic differences and for individual needs and wants. Menus would be an answer, they say.

Residents discussed the importance of budgeting for higher quality foods in order to provide a well balanced and nutritious diet for residents.

The groups say meals should be served on time, graciously, and hot. They want more seasoning and less bland food, as well, as appropriately sized servings.

Residents in the study place high value on professionals in planning and supervising food service. They also say cleanliness, efficiency and the use of modern equipment are important.

Residents particularly want input in planning, advising and monitoring of nursing home food service.

CHOICES

Choices about food, when to get up, and when to go to bed were the major areas residents identified in this study. Residents expressed their desire for freedom to come and go as they would like within the nursing home, and outside the home as well. Choice of activities and whether or not to participate also ranked high in importance for the residents in this study.

Residents say they would like choices in roommate assignment, bathing schedules, personal care attendant and physician. Residents would like to be able to choose medications they take.

The issue of residents' rights arose in discussions about choice. Residents say that the Residents' Bill of Rights should be a part of orientation for every new resident and staff member, and should be laid out clearly to residents, available for them to consult at all times.

In the discussions, residents cited the Resident Council as the means to assure that rights are observed. Residents in this study mention a number of additional ways to ensure rights and choice's, including more staff responsiveness and support for resident choices.

Participating residents say that residents should speak up and assert themselves about making choices, individually and through groups, including the Resident Council.

PROBLEM SOLUTION

Residents cite the Resident Council, the administrator, staff, social workers, families and relatives, and the ombudsman program as channels to be used to solve problems. They indicate their awareness of appropriate and effective ways to solve problems in a nursing home. They want to be involved in finding solutions. Residents related this to their rights and to self-determination.

These residents recognize that the personal feelings and attitudes of staff and residents affect problem development and resolution. Therefore, they propose solutions that strengthen relationships, cooperation and sharing, or, as one resident says, "Love and understanding."

When asked about the less able, residents say other persons should take a role in problem solution on their behalf, including family, staff, volunteers and more able residents.

According to the participating residents, the policies about problem resolution should be explicit and made known to residents. Residents said it is important that problem resolution policies are carried out consistently and that all persons are treated equally so that residents can rely on the policies.

QUALITY CARE ISSUES

Choices and the right to make them are primary markers of quality care, according to the discussion groups. Residents say choices in activities, about foods, living arrangements, personal care and other dimensions of resident lives are important.

In the discussions, residents cite a pleasing and happy homelike atmosphere as desirable. They value an environment that makes life safe and secure, physically and emotionally.

Participating residents say good feelings and attitudes between residents and all levels of staff, and among residents, are essential to quality care and quality of life in the nursing home.

Individualization and personalization rank high with discussion participants. Residents say they want as much independence as possible, whatever their level of ability, and they want the opportunity to help themselves whenever possible. If help is needed, residents say they would like it given cheerfully, with understanding. They say they are willing to provide help for the less able.

When residents talk about quality care for the less able they identify the need for more care, visitors and attention. This can be provided by other residents, by staff, volunteers and family. Independence and choice are important for the less able, too, to enhance the quality of care and life for these residents.

Residents indicate the desire for normalization of their lives, a homelike setting and independence and choice.

GOVERNMENT RULES

When residents discussed how the government's rules can help ensure quality care, they most frequently addressed the importance of rules requiring staff training. Residents also stated the importance of their continued input into the workings of the home.

Residents offered suggestions for improving the quality of care through additional regulations for administration, for staff performance standards, and for supervision. Participating residents discussed the need for monitoring by residents, volunteers and families, and for a union or public role to enforce regulations.

Residents suggested a rule that requires policy-makers, inspectors and all staff to spend some time living in a nursing home. They felt this would give them a resident's perspective.

The importance of training about rules is, underscored. Residents in the groups state that there should be training for staff and for residents about regulations. Residents can maintain an active self-advocacy role, they say, if they are trained. They need to be aware of what the rules are and how to have access to them.

Residents in the groups discussed their role individually and through the Resident Council in monitoring compliance. They discussed the value of probation, fines or other disciplinary actions, including closing a home, when rules are not followed.

INSPECTION

Residents discussed the importance of a role for themselves, and for the less able, in the inspections. They stated their belief that residents should have the opportunity to talk freely with inspectors .

More than half the groups expressed strong feelings about participation in inspection and almost all groups described an expanded resident role, particularly when answering the question, "What would you tell the inspectors to look for to know if good quality care is being provided?" "Talk to as many residents as possible," some residents say.

Participants in the project thought group discussion would enable residents to take part in inspections effectively.

Residents discussed the possibility of family interviews during an inspection, particularly to speak for the needs of the less able. Residents also see the Resident Council and volunteers as possible representatives of less able residents. It is important that the inspectors see and talk to the less able, group participants said.

BRINGING ABOUT QUALITY CARE

Residents in the discussion groups were asked to identify the ways that quality care could be brought about and what could be done by the community, the family, nursing home administrators and staff. Residents also discussed the role they could take to insure that quality care is brought about.

Residents first indicated that staff was the most important factor in achieving good quality care: positive staff attitudes, well-trained and efficient staff. Residents also believe that money could bring about quality care.

Residents say that if the community visits nursing homes and participates in activities within the home, this will have a positive effect on nursing home life. Residents expressed the importance of active involvement by the community.

They felt that community involvement would change the negative stereotypes held by the community and break down the barriers between the community and nursing homes.

Publicity and the media would also help to change the ideas the community has about residents. Residents would like the community to take a more active role in monitoring nursing home care as well.

Families can visit and serve as a link between the home and community. The creation of active family councils, which can monitor care, was cited by residents as a means to bring about quality care and life. The tasks that families perform for residents can also contribute to quality care.

Residents said that nursing home administrators should get out of their offices and spend more time out in the nursing home, to make themselves aware of what is going on in the home. Supervision of the staff by the administrator was cited as especially important.

When asked about the ways that staff can bring about good care, residents identified the importance of good staff attitudes, as well as staff doing their job well, and reporting things they observe within the home.

Residents believe they can have a role in bringing about quality care. They would like to have an active role and take on more responsibility for their own care and lives. They say they want to be advocates for themselves and stressed the importance of speaking up.

They also cited the value of their relationships with each other, seeing mutual support and cooperation as important for bringing about quality care.

NATIONAL SYMPOSIUM ON QUALITY CARE

The National Symposium on Quality Care was a historic first for many reasons. It was the first national symposium on quality care from the residents' point of view. It was the first national meeting attended by so many nursing home residents from across the country. It was the culmination of the first research project based on residents' discussions of quality care. It was the first meeting at which residents, health care professionals, educator:, researchers, advocates, and regulators met together to exchange ideas and experiences from their various perspectives.

Amidst flashing cameras and heightened excitement, nursing home residents convened in a pre-Symposium session to meet each other, share tales of their cross country venture and exchange strategies for getting things working back home. At the meeting they were introduced to the National Coalition of Resident Councils and heard, same for the first time, of activities throughout the country in which residents were organizing and speaking out. Fifteen area nursing homes responded to the request of the local long term care ombudsman council and donated staff to assist residents during their stay.

Over one hundred participants met for three days at the Sheraton hotel-turned-nursing home at Clearwater Beach, Florida. The opening session placed the meeting in its historic context by honoring two pioneers in the fields of resident involvement and quality care. Honoree Herbert Shore, administrator of Golden Acres Home for the Aged in Dallas, Texas, who first initiated resident councils in his home in the early 1960's, gave the keynote address, explaining both the simplicity and the importance of resident participation. Honoree Ruth Knee, who -chaired NCCNHR's Advisory Panel for the project, had as a civil servant convened a landmark national meeting on residents' rights in nursing homes in ,the mid-1970's. She challenged participants to make history at this symposium as well.

The Symposium was structured around three major presentations in which long term care professionals responded to the report of the residents' discussions from the perspective of their various professions. Presenters were asked to react and respond to the report and to discuss what their professions could do differently to bring about the type of care residents described.

The first panel, entitled Implications for Service Delivery and Quality Assurance, included presentations by a nursing home administrator, a nurse, a physician, and a social worker. Presenters highlighted the conflict between professional responsibility and personal responsiveness and suggested a variety of professional practices to bridge the gap. They advocated high touch over high tech; function over infirmity; community over isolation; caring over care. They challenged their peers to uphold their first responsibility: to listen to residents.

This theme resounded in the second panel, as well. Entitled Implications for Education, Training and Research, it emphasized the need for a new educational agenda for health care workers to teach.