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# A training workshop on late-stage dementia care for family caregivers

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## Abstract

*Training workshops have been considered a useful intervention in helping family caregivers of people with dementia to cope with the stress of caregiving. However, there are no reports in the literature with regard to training and support of families specifically looking after individuals who are in the late stage of dementia. This paper reports the experience and evaluation of a training workshop aimed at preparing family caregivers for late-stage dementia care. Eighty-eight percent of the participants completed the client satisfaction questionnaire. The results from the questionnaire gave a very positive response, showing 90.9 percent of respondents were satisfied with the workshop, and 77.3 percent of respondents indicated that their caregiving needs were met. Eleven participants who attended this workshop joined a focus group feedback session. The Kruskal-Wallis test found no significant differences between the overall profile of the participants and that of the focus group in terms of age, gender, educational background, whether they were primary caregivers, for whom they cared (e.g., parents or spouse), or whether the care recipient stayed at home or in a nursing home. Findings from the focus group session provide a somewhat different picture from that of the questionnaire. Three focus group participants provided more critical comments of the workshop. Although the majority of the focus group*

*agreed that the workshop had been useful, they disagreed on whether it is necessary to discuss psychosocial issues in this workshop. Findings from the focus group have enabled the project team to reflect on their design and operation of the workshop and provided valuable insight for future development as well as for further study.*

*Key words: caregiver training, caregiving, dementia, educational workshops, focus groups, late-stage dementia care*

## Introduction

Discussion of training and education provided for family caregivers of people with dementia abounds in the literature. The primary focus of workshops delivered for enhancing family caregivers' abilities in caring for their loved ones afflicted with dementia has been on managing emotional and behavioral problems and finding ways to obtain resources and supporting services. These topics are more relevant to families that are caring for those in the middle stage of dementia, when the affected individual stays in the community. Early-stage dementia care is gradually getting more attention from professionals as well. However, late-stage dementia care is often perceived as requiring full-time and intensive care in an institutional setting.<sup>1</sup> There is limited discussion on support and training workshops for families caring for their elders with dementia who are in the late stage of their illness.

Reportedly, decisions for nursing home placement are difficult to make,<sup>2,3</sup> and many family caregivers will care for their relative with dementia at home as long as they can.<sup>4-7</sup> Still, although many family caregivers look after their relatives until the advanced stage of dementia, there are others who need to place their loved ones in an institution toward the late stage, when the functional abilities of

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those with dementia are severely compromised.<sup>8</sup> Studies also inform us that caregiving does not end when a loved one has entered an institution.<sup>9,10</sup> Families look for ways of actively participating in care and want to help their loved ones to have a better quality of life through their regular visits and involvement in decisions about care. Regardless of whether these individuals with dementia are at home or in institutions, family caregivers need information and advice as to how they can provide support and better care for their loved ones.<sup>11-13</sup>

This paper will report on the conceptualization, design, and evaluation of the late-stage dementia care training workshops, jointly organized by the Community Rehabilitation Network (CRN) and the Hong Kong Alzheimer's Disease and Brain Failure Association (ADA).

## Conceptualization of project

The two associations, CRN and ADA, have been working together to provide support to family caregivers of people with dementia for over five years. Most of the time, the organizations offer training workshops that cater to the needs of families caring for relatives in the middle stages of dementia, as it is the most in demand. In the last couple of years, workshops for early-stage dementia care have also been offered. Through first-hand experience, the project team observed that materials provided in the middle-stage workshops were not addressing all the needs of caregivers. Many caregivers participating in the middle-stage workshops were, in fact, looking after their relatives who were in the middle-to-late stage, or late stage, of their illness. Therefore, CRN initiated this workshop.

## Uniqueness of the project

Training and support for late-stage dementia care mainly focus on the needs of the formal caregivers, such as nursing home staff.<sup>14</sup> The needs of family caregivers in this regard have rarely been addressed in the literature. Searches in the health and nursing databases found no studies or discussion in the area of training workshops for families looking after their relatives at the late stage of dementia. Late-stage dementia care is often conceptualized as care provided in long-term care settings. Much discussion has focused on end-stage dementia care issues such as comfort and feeding. Whether it is due to the expectations that people who are in the late stage of dementia are more likely to be in long-term care settings is not known. The late-stage dementia care training workshop, a community-based intervention jointly provided by CRN and ADA, is therefore a unique service. The workshop has two notable features: first, it is generated from clients' "demand"; and, second, the focus is skill-based.

The workshop contents are developed along the lines of questions commonly asked by family caregivers. Families who came into contact with the two associations raised questions such as, "My father just holds his mouthful and won't swallow." "She was sitting there all day in her home. Her legs become stiff." "I have so much trouble moving my husband from bed to his wheelchair and then from wheelchair back to his bed. My back is sore all the time." "Every time I saw her condition deteriorated further, I am frustrated at my own helplessness." Almost the entire content of the workshop is developed along the line of families' verbalized needs.

The workshop's second characteristic is that it is skill-based. It is designed with the aim of supporting families in late-stage dementia care in the techniques of caregiving. The literature informs us that families would not be satisfied eventually with just having support for psychosocial care, but asked for training in practical skills of caregiving.<sup>15</sup> In our workshop, not only psychosocial skills, such as relaxation or how to deal with one's own emotions, are discussed, but also practical skills like turning and transfer are taught.

## Project design

The workshop has two main objectives. First, to teach family caregivers practical skills in looking after individuals with dementia. Second, to help prepare family caregivers psychologically for further deterioration of their loved ones. On the basis of questions frequently asked by families, the workshop is designed to cover the areas of personal care, pressure sore prevention and management, swallowing and eating issues, transfers and mobility exercises, decisions about long-term care, and dealing with loss and issues in communication.

Since implementing the workshop in 1999, three rounds of the workshop have been conducted. There have been continuous revisions in its presentation, progression, and contents. However, the key components of the workshop have not changed. A social worker and a nurse, both specialized in dementia care, are the facilitators of the workshop. Each session consists of knowledge dissemination, teaching of skills, supervised practice, and group discussion. The facilitators actively engage participants in sharing among one another during each session. Staff or volunteers from ADA are present to introduce participants to monthly support groups, family support networks, and other relevant local resources. (See Table 1.)

The first session covers the area of disease progression and personal care issues. The discussion on disease progression, symptoms, and behavioral presentation of a person in the late and final stage of dementia aims at setting the stage for the discussion topics to follow.

**Table 1. Outline of workshop contents**

| Session | Topic   | Speaker            |
|---------|---|--------------------|
| 1       | Disease progress and personal care issues   | Nurse              |
| 2       | Pressure sore prevention and management   | Nurse              |
| 3       | Swallowing difficulty and management  | Speech pathologist |
| 4       | Nutrition and preparation of food   | Nurse or dietician |
| 5       | Transfer and exercise   | Physiotherapist    |
| 6       | Dealing with loss, decisions on institutionalization, and issues in communication | Social worker      |
| 7       | Post-workshop gathering   | Social worker      |

The maintenance of personal hygiene in dementia care, such as bathing or showering, is the topic of the second session. Because the topic covers several areas, the discussion is designed to be client-led. For example, in the first round of the workshop, participants asked a lot of questions on tooth brushing, use of dentures, and dental hygiene, whereas, in the second round, families wanted practical tips about bathing and continence care.

The third session features a speech therapist, usually a volunteer from ADA, speaking on the topic of swallowing. Within this session, the speech therapist briefly introduces normal swallowing and pathological changes in dementia. Some practical tips on how to facilitate swallowing are taught, for example, the use of a drop of diluted lemon juice to stimulate the sense of taste. The speech therapist also introduces how therapeutic service can be accessed and referrals can be made.

Either a nurse or a dietician leads the next session, concerning nutrition and food preparation. This session focuses on families' concerns about nutritional problems that their relatives with dementia may have. Topics include nutrition for people in late-stage dementia illness, how to prepare nutritious yet inexpensive food for individuals who are gradually losing their power to chew and swallow, and how to make food more enticing. Part of the session is devoted to discussion of nasogastric tube (NGT) feeding or percutaneous endoscopic gastrostomy (PEG). Feeding of demented individuals who refuse to eat or can no longer do so has been an issue of intense debate among professionals in the Western literature. However, locally, where the predominant population is ethnic Chinese, feeding and eating are very

important issues. In almost all cases, families found the idea of not feeding their relatives and letting them "starve" to death to be horrifying and unacceptable. Forced feeding or prolonged suffering as a result of continued feeding appears to be a nonissue when compared with the concern of starving a person to death. Nevertheless, the workshop facilitators would try to introduce the topic of NGT or PEG feeding as an option, not as a matter taken for granted when an individual can no longer eat.

The topics for the fifth session are transfers and mobility exercises. A physiotherapist, assisted by physiotherapy students, teaches techniques including the transfer of an individual from bed to chair and vice versa; some light active exercises, and passive stretching and range of motion exercises. Sometimes the use of a wheelchair is also included in the discussion if time permits.

The sixth session centers on the issue of long-term care placement. This last session also discusses how to deal with the loss of loved ones, either in the sense that he or she no longer recognizes the caregiver, or that he or she would eventually be lost to progression of the disease. The session is intended to be an exploratory one and is not meant to probe deeply into families' emotions. The workshop facilitators are always aware of those who may become very upset as a result of discussing this topic. Families are either actively approached for follow-up discussion or are advised to approach the facilitators for further discussions or counseling.

The last session is a reunion aimed at providing a chance for the families to come together again for sharing and mutual support after their discussion on long-term placement and the loss of their loved ones.

**Table 2. Workshop enrollment and attendance**

| Round   | Enrollment (participants) | Actual participants | Drop out number of persons (percent) | Mean attendance (percent) |
|---------|---------------------------|---------------------|--------------------------------------|---------------------------|
| 1       | 17                        | 16                  | 1 (5.9)                              | 82.3                      |
| 2       | 13                        | 11                  | 2 (15.4)                             | 93                        |
| 3       | 11                        | 9                   | 2 (18)                               | 86                        |
| Average | 13.3                      | 12.3                | 1 (8)                                | 87.1                      |

## Workshop evaluation

### *Workshop participation*

Participants learned of the workshop through a number of means—newsletters and pamphlets, posters in clinics, word of mouth by family caregivers, and sometimes through referral from health care agencies.

Confirmation that the cognitively impaired relative these participants looked after was at the late-stage of dementia was not a requirement for enrollment in the workshop. The social worker responsible would call the family and inquire briefly about the condition of the relative with dementia. If information from the family showed that the relative seemed to be in the earlier stages of illness and the family had not attended the training workshop for middle-stage dementia care, the social worker would suggest it might be more appropriate and beneficial for them to attend other training workshops that offer a program better suited to their needs.

Responses from the workshop participants have been good, as reflected in the low dropout and high attendance rates. Table 2 shows the figures for enrollment and attendance at the three rounds of workshops. There were 16, 11, and nine participants in the three rounds of workshops, respectively. The mean dropout rate was 8 percent and the mean attendance rate was 87.1 percent. A point to note is that four out of 37 participants (10.8 percent) took part in this workshop more than once. These participants were insistent that they needed to refresh their skills.

Table 3 is a description of the demographic and other characteristics of the participants. Mean age of the participants was 48.5 years (standard deviation [SD] = 9.82). Females represented a large portion of the family caregivers (88.9 percent). Most of the participants belonged to the 40 to 50 age group (44.4 percent), those aged 50 and over constituted 36.1 percent, while those under 40 formed only 19.4 percent. The majority of the

participants were the primary caregivers (86.7 percent). We refer to primary caregivers as those who were either living with or primarily responsible for taking care of the relative with dementia in the family. Most people looked after their parents (80.4 percent), with spouses coming next at 14.6 percent, and siblings and grandparents constituting 2.8 percent and 2.2 percent, respectively.

Since clinical assessment of the individual with dementia was neither required nor performed, staging of the disorder could not be confirmed. On the basis of the information from the families, the clinical impression of the social worker enrolling the participants was that 28 (75.7 percent) of the participants had relatives in the late-stage of dementia. Common criteria in staging of dementia disorders, including the loss of verbal abilities and basic psychomotor skills such as eating, walking, and toileting,<sup>16</sup> are used by the social worker in the process of staging. Although most participants' relatives were in the late stage of dementia, a fairly high percentage (59.6 percent) remained at home. The rest were already admitted into nursing homes or were staying in hospitals at the time of data collection (40.6 percent). In the first round of the workshop, a couple looking after the same parent attended the workshop. The rest of the participants joined the workshop on their own, not accompanied by any other family members. Therefore, in the final reporting sample, there were 37 participants, but 36 families.

### *Feedback on the workshop*

Upon completion of the workshop, the project team collected some feedback from participants using a client satisfaction questionnaire devised by the team. A four-point Likert scale was used with 1 indicating “strongly disagree”; 2 for “disagree”; 3 for “agree”; and 4 for “strongly agree.” The administration of a client satisfaction questionnaire is a routine practice for all CRN workshops, and clients were not required to provide identifying

**Table 3. Characteristics of participants joining workshops**

|           | Number of participants | Age        | Gender       |              | Primary caregiver | Looking after whom   | Staying at home or Nursing Home (NH)    |
|-----------|------------------------|------------|--------------|--------------|-------------------|--|---|
|           |                        |            | M            | F            |                   |  |   |
| Mean (SD) | 12 (3.61)              | 48.5 (9.8) | 11.2% (14.3) | 88.9% (14.2) | 86.7 (13.7)       | Grandparent 2.2% (3.9)<br>Parent 80.4% (2.8)<br>Spouse 16.6% (7.0)<br>Sibling 2.8% (4.8) | At home 59.6% (12.3)<br>NH 40.4% (12.3) |

\* No significant differences were found in the characteristics among the three rounds of participants.

information of any kind. Unfortunately, in terms of evaluation, this means that the following results also included the 10.8 percent of participants who attended the workshop more than once, and their responses could not be differentiated from those of first-time participants.

A total of 33 participants completed the questionnaire, with a mean response rate of 92.1 percent. The overall appraisal of these workshops was good (mean score [ms] of all items = 3.17). There were only occasional responses showing strong disagreement with the usefulness of the content, organization and teaching of the workshops. In fact, most negative responses came from one participant. The two items most people were dissatisfied with were time allocation (ms = 2.87) and whether the workshop met their caregiving needs (ms = 2.75). Most participants stated that the sessions were too short. The majority of the participants agreed that the workshop was practical (ms = 3.38), had adequate depth and breadth (ms = 3.13) in its content (ms = 3.38), and met their expectations and caregiving needs. Generally speaking, they were satisfied with the overall running of the workshop (ms = 3.13) and will recommend the workshops to their friends (ms = 3.63). (See Table 4.)

For the last workshop, the team decided to have a more structured evaluation and to use focus group techniques to provide more in-depth understanding in terms of evaluation. A letter was sent to all individuals or families who had participated in the three workshops, inviting them to attend a focus group meeting. Eleven participants joined the focus group session. Participants from the most recent round of workshops formed 36.4 percent (n = 4) of those attending the focus group session. Kruskal-Wallis tests were used to determine whether there were significant differences between the profile of the three rounds of participants and that of the focus group. No significant differences were found between the groups in terms of age (df = 3; P = .925),

gender (df = 3; P = .240), whether they have had secondary education (df = 3; P = .329), whether they were primary caregivers (df = 3; P = .327), whether they were looking after their parents or spouse (df = 3, P = .963), or whether the care recipient stayed in the home or a nursing home (df = 3; P = .767).

Another social worker, who was not involved in any aspect of the workshops, facilitated this focus group meeting, using a semi-structured interview guideline. Key questions included asking the participants what they had gained from the workshop, in what ways they found the topics useful, and whether the workshop met their expectations. Audio recordings were transcribed verbatim. The project team read and reread the transcribed information to delineate key areas brought up by families. Any disagreement in data analysis was discussed until team members reached a consensus. Finally, the focus group facilitator validated findings by the team.

### *Findings from focus group*

Those areas that participants found helpful included, first, practical skills. The skills they said they learned included how to change position (turning), prepare suitable food, perform passive exercises, manage simple bedsores, and maintain general hygiene for their relatives with dementia. Five of them (45.5 percent) mentioned that they liked the session on how to handle their own emotions because it gave them an opportunity to let go of their feelings. More importantly, they said they were able to come to know a group of people sharing similar experiences to support each other. Among these five participants, one mentioned that she joined the workshop more than once because she was able to learn something new each time. It also gave her an opportunity to refresh the skills she learned. Two participants said that whether they were able to apply the skills they

**Table 4. Means and standard deviations—Client Satisfaction Questionnaire**

| Question items<br>Total number of workshop participants = 36<br>Number of completed questionnaires = 33<br>Mean response rate (3 rounds of workshop) = 92.1% (SD 6.9) | Responses<br>1 = strongly disagree<br>2 = disagree<br>3 = agree<br>4 = strongly agree |     |
|---|---|-----|
|   | Mean  | SD  |
| 1. Practicality of knowledge and practical skills introduced  | 3.38  | .52 |
| 2. Teaching of practical skills   | 3.13  | .35 |
| 3. Time allocation of each class  | 2.87  | .35 |
| 4. Overall arrangement of workshops   | 3.14  | .38 |
| 5. Depth of content material  | 3.13  | .64 |
| 6. Breadth of content material  | 3.38  | .52 |
| 7. Overall satisfaction with the workshops  | 3.13  | .35 |
| 8. Met own needs in caregiving  | 2.75  | .71 |
| 9. Met own expectations   | 3.13  | .64 |
| 10. Will recommend the workshops to friends   | 3.63  | .52 |
| Mean score of all items   | 3.17  | .25 |

learned depended on their relatives' stage of illness. These two participants said that, even though they were not immediately able to use the skills, they found the workshop helpful because it oriented them to possible future developments.

There were areas that some participants did not like. Overall, there were three participants (27.3 percent) who had some negative comments on the workshop. The areas they found to be unsatisfactory related to the sessions that could not address the need of an individual whose relative's condition might be very different from that of the others. One participant said that the sessions did not introduce how to use braces for maintaining limb alignment, how to observe an individual who had lost the ability to tell his or her caregiver what the problem was, and how to perform chest physiotherapy for their relatives. Another participant verbalized that the workshop should teach them what to look for when they needed to purchase equipment. She also stated that the workshop should include teaching participants how to use assistive devices (such as air mattresses) and where to borrow assistive devices or aids (such as wheelchairs) on a temporary

basis. These two focus group participants also felt quite strongly that they did not appreciate the session on dealing with the loss of a loved one. One of them considered it impractical to include a discussion of psychosocial issues, as there was already inadequate time for practical skills. The other indicated that the caregiving experience was already very painful and she did not want to be further reminded.

However, there was one participant who highly complemented the workshop. She stated that, although she did not yet need to use the skills she learned during this workshop, it nevertheless gave her an overview of what she might need later. She felt that the greatest use of the workshop was to heighten her awareness of the various issues in caregiving so that she was better prepared. She felt that when her family had to face similar situations (*e.g.*, problems in continence, turning, or feeding), she would know what to do and where to get help. She found the session on dealing with the loss of a loved one to be helpful for the same reason and defended the necessity of having this session.

At least three participants (27.3 percent) in the focus

group were quiet and provided limited feedback. The comment with which most focus group participants agreed was that sessions were too short, such as the one by the speech therapist. Another comment they generally agreed upon was that asking family caregivers to share their experience was useful in the sense that they were able to provide practical tips on the home situation.

From the focus group findings, no differences were noted in the evaluation of the workshop by participants who were looking after their relatives at home or had their relatives placed in nursing homes. Among the three focus group participants who provided some negative feedback, one cared for her relative who lived in a nursing home, while a couple (as mentioned above) looked after their relative at home. Of the three focus group participants who thought highly of the workshop, two of them looked after their relatives at home, while one already had placed her family member in an institution.

### *Discussion*

Comments from the participants' feedback can be summarized into the following points. First, participants evaluated the usefulness of information in terms of its practicality. They also would like more practice and individual feedback for the skills they learned. Second, many found sharing with experienced family caregivers to be useful. Some participants found family members' practical tips and ideas to be a useful complement to professional input. Topics participants found helpful included positioning and transfer, preparation of food, passive and active exercises for their relatives, simple wound management, continence management, and how to maintain general hygiene. Topics not discussed in the workshop, but which were deemed important by the participants, included chest physical therapy, continence management, application of limb braces, and resources concerning purchasing or borrowing equipment for use at home. Although the overall consensus was that each felt that they learned something, three of the 11 participants in the focus group were more critical of the workshop.

One controversial issue among participants was whether there was any need for discussing the coming loss of their loved ones with dementia. Participants who were against including this session already found the emotional burden in looking after their relatives too much to deal with and preferred not to think about this topic at all. They would rather have the time spent on discussion of practical skills. The participant who supported inclusion of this topic argued that it helped to prepare her psychologically for dealing with the future.

The situations of individual family caregivers were different, leading to different expectations of the workshop.

Consequently, participants appraised the usefulness of the workshop quite differently. For example, the participants who were more critical of the workshop stated that practice skills should be the focus of a workshop and urged that we dispose of the more theoretical sessions (such as stages of the disease and the psychosocial part). Their appraisal of the workshop seemed to be based solely on its skill aspects. Others did not show such a strong feeling about each different session, and they evaluated the usefulness of the workshop in a general way, finding all sessions to be generally useful. As mentioned earlier, there were five members who were appreciative of the sharing with each other and how they felt about caring for their relatives. These participants found their new connection with other caregivers to be a valuable feature of the workshop. There were yet others who expected to have all specific questions on their relatives' particular situation addressed and consequently appraised the workshop in terms of whether these individual questions were answered.

Although our client satisfaction questionnaire indicated high levels of client satisfaction, feedback from the questionnaire did not give specific information concerning various aspects of the workshop. The focus group discussion provided feedback from workshop participants of a greater depth. Findings from the focus group informed the team of various aspects of the workshop that needed rethinking and improvement.

In the future, participants should be enabled to become more involved in the conducting of the workshop. For instance, participants could be informed of the content of each session in better detail, particularly the ones concerning dealing with losses and decisions on placement. This way, participants could negotiate between themselves and with the workshop facilitator whether they wanted specific topics, how certain topics could be presented, and how best to approach some topics.

The team gained the sense that some participants wanted information beyond the basic level and expected to learn in-depth assessment and management skills through the workshop. The team has reservations concerning this feedback. The team believes that participants need to be clear in regard to the objectives of the workshop. Participants should be taught to recognize the signs that something is going wrong and when to seek professional help. We do not believe that families are unable to master certain advanced skills and in-depth knowledge of caregiving. As with parents who look after their chronically ill children at home and are taught to master complex skills such as ventilator management, we believe that families also can learn skills such as pressure ulcer treatment. However, families need to learn these skills under more intense supervision until they

become proficient, and practice them until the supervising professionals are satisfied with families' performance prior to independently performing the skills at home. Unfortunately, such an intense level of family education and support is uncommon in Hong Kong due to a poor integration of services between health facilities and home care.

Information from the participants was valuable in that the project team was able to reflect on the planning and organization of this workshop for improvements in the future. The diversity of the membership of these groups rendered it a challenge for the project team to cater to the needs of individual participants. In fact, the team noted that in each round of the workshop, each group had its own dynamics and needed to be treated differently. Due to the diverse background of these group members, very experienced professionals will be required to deal with their multiple questions and diverse needs. This is a major recommendation of the team to professional colleagues who would like to conduct similar projects.

Findings from the focus group also point to future study directions. For example, what are the needs of families looking after their relatives in the late stage of dementia at home? This essential question has not been systematically addressed prior to our project. What are the areas about this workshop that families found useful? Was it the teaching, the practice, or the networking and sharing with other families? Does the workshop bring about any changes in caregiving? How do we know that classroom learning of participants can be transferred to their home setting? These are questions that require further investigation.

## Conclusion

Support for family caregivers in the late stage of dementia care has drawn limited attention from researchers and clinicians alike. This joint project between CRN and ADA is an attempt to meet the needs of families to address this service gap. The team would like to think that a unique service need of caregivers for people with dementia has been addressed through this workshop. Responses from the client satisfaction questionnaire showed that the majority of participants agreed that the workshop met their expectations and needs. However, the focus group findings revealed that three of 11 participants (27.2 percent) were more critical of the workshop. Nevertheless, these three participants agreed that there were valuable aspects of what they had gained in the workshop. Through participants' feedback,

the team was able to identify areas of planning and organization for future reference. Better publicity and long-term scheduling are needed. The workshop also needs to be very practical, and members should be encouraged to voice their explicit needs and preference as to how the workshop is to be conducted. Peer sharing and networking should be promoted, as this was an aspect that many participants found useful. The team also recommends that CRN and ADA need to establish partnerships with health care facilities so that there can be a better interface between hospital and community care.

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