The RUSH Project

Major findings from:
Determining the effectiveness of a collaborative support model to train community-based care providers how to implement AAC with persons who have Alzheimer's disease in community settings
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What is RUSH?

RUSH stands for **Research Utilization Support and Help**.   RUSH projects are designed to help researchers bring their results to the communities that could use them. This project was funded through the Southwest Educational Development Laboratory with support from the National Institute on Disability and Rehabilitation Research.

What is the purpose of the RUSH research project?

The goal of this research project was to familiarize long-term care providers in accredited Alzheimer's Care Units (ACUs) with Augmentative and Alternative Communication (AAC) and the strategies and tools associated with AAC so they can consider using them with the people for whom they care.   RUSH also was intended to determine awareness and knowledge of AAC practices before and after the trainings, and the level of AAC use before and after the trainings in the ACUs.

What is AAC?

When we think of how people communicate with each other we generally think of speaking and writing. But these are not the only forms that communication can take. Augmentative and Alternative Communication was developed to expand the ways in which people can communicate and to expand how we think about communication. An AAC device or technique can be many things; basically it is anything that supports communication by reducing the demands on the speaker. We all commonly supplement our speech with gestures, facial expressions and even pictures to share information, opinions and other content. We laugh and cry. Our body gestures speak for us too. People who are blind may use Braille. Computers may talk. These are all AAC techniques. Boards with pictures on them, talking toys, and communication binders and albums are also AAC devices.

How do we think AAC training for caregivers may benefit people with Alzheimer's disease?

People with Alzheimer's disease (AD) gradually lose the ability to communicate as their memory becomes less reliable. Their ability to remember words decreases. Eventually even events of importance may fade from memory.   Research has suggested that AAC may provide tools to help them retain the ability to communicate for a longer time.   But knowledge of these tools is limited among care providers in ACUs.   The purpose of the RUSH project was to develop a protocol to teach caregivers about AAC and to document its effectiveness. It also was designed to measure the effect of training on AAC use in ACUs.

What were the major activities of the project?

First the team of researchers developed a training curriculum to present to the ACU care providers. The content of the training included information about AAC and the specific AAC device that we provide for the caregivers to use if they wish.

The state of Oregon requires that training workshops be provided to licensed long-term care providers in ACUs. Our training was delivered as part of these workshops in 9 ACUs in the Portland, OR area by Joyce Beedle, an Alzheimer's disease Educator who teaches these workshops for the state of Oregon. The materials were provided in English and Spanish and participants were invited to ask questions and discuss the information. Participation in the research was voluntary; and individuals could choose simply to attend the workshop to satisfy the state's requirements.

The AAC device that was provided through the workshops (shown above) was developed based on earlier research that pinpointed the most effective methods to support conversations by people with Alzheimer's.   We call the device a SpeechKIT. It consists of a flat plastic box with a hinged lid that contains 32 labeled photographs. The photographs were picked because of their likelihood of relating to elders' memories of Oregon. For example, there are labeled pictures of Mt. Hood, Haystack Rock at the coast and of a tree. The top of the box has two strips of Velcro and each photo has Velcro on the back. Up to six pictures can be displayed on the top of the box at one time. By presenting the labeled

pictures to the residents, the caregivers can provide them with possible subjects of conversation and with the words they need to discuss the subject. They can refer to a picture and ask, "What shall we talk about today? Did you ever go to Mt. Hood?" The caregivers who participated in the research assembled the kits themselves during the workshop, using materials that we provided. The ACUs kept the SpeechKITS to use as they saw fit. Some facilities took several, some only a few. This varied partly with the size of the facility, and also with the number of caregivers who participated.

Before taking the workshop participants completed a questionnaire to measure their level of knowledge of AAC. They completed the same questionnaire several times after the initial training. This enabled the researchers to compare the caregivers' level of knowledge before the training and after, so they could evaluate the success of the training.

Learning about a tool or technique and using it are two different things. The next step was to conduct observations at the ACUs to see whether they used the AAC devices. We developed an observation form which provided a way to collect information about the actual use of the SpeechKITS or other AAC devices in the ACUs. The forms provided places to record the number of conversations started by the caregivers, the number of conversations started by the residents, whether an AAC device was present, and whether the use of AAC, when it occurred, was brief or extended.   To conduct the observations several research assistants went into the ACUs to observe. The number of assistants depended on the size of the facility.

The last task for the caregivers who participated in the workshops was to complete a satisfaction form. This form was intended to collect feedback data on the value of the workshops to them. Unfortunately the information collected didn't provide reliable information that could be used to evaluate the workshops. So we interviewed the administrators who had participated in the project, asking questions that would enable them to evaluate changes in awareness, knowledge practice or policy as a result of the training and the materials that were provided. Also, we interviewed Joyce Beedle, the person who gave the workshops, to glean her insights into the impact of training and lessons to inform future efforts of this nature.

How was the RUSH research structured?

The RUSH project involved a team of university based clinical researchers, a community AD educator, a gerontology-certified project coordinator, and staff/administrators from nine ACUs.

The project divided the nine facilities into three groups. One was the control group, which involved three of the ACUs, and whose staff didn't participate in the workshops. All they did was complete the questionnaires.   The second and third groups each involved three ACUS and a total of 93 caregivers. Participants in both of these groups took the training, but at different times. The questionnaires were given on four pre-set dates to all three groups, once or twice before starting the training and two or three times after its completion, depending on the group.

Before any training had been given, research assistants went into the ACUs and conducted observations to see what level of AAC use was occurring, if any, and what that use looked like. The research assistants returned twice more to observe and again took data on the use of AAC in the facilities so that a picture could be drawn of the effect of the training on AAC use at each facility.

What did we investigate, what did we expect, and what did we find? This project had four major aims. Below we review those aims, what we expected our data to show, and what it actually showed with regard to each aim.

Aim 1: To measure the difference in awareness and knowledge about AAC of ACU caregivers before they took the training and after they took the training. We thought that after they participated in the training the caregivers would show an increase in awareness of the usefulness of the AAC device for the AD residents, would have a greater understanding of the communication difficulties of the residents, a greater understanding of the potential of AAC devices for them, and understand how they might create other AAC devices.

What we found: We found a significant increase as measured by the questionnaires in understanding and awareness of AAC and of the usefulness of AAC devices for AD residents for a period of time after the training. But, as the length of time after the training increased, retention of the material decreased.

Aim 2: To see how frequently AAC devices were used before and after the training of their care providers. We thought persons with AD would use the AAC devices more often after their care providers received the training than they did before the training.

What we found: We compared the combined number of resident and caregiver initiations of AAC use from our observations before and after the trainings. We found that after they participated in the workshops, the centers showed a significant increase in the use of the AAC devices. We also looked to see if there was an increase in extended AAC conversations between the residents and their caregivers (as compared to brief exchanges) after the trainings.   We found significantly more extended AAC conversations immediately after the training. We did not find an increase in the number of AAC conversations initiated by the residents. However, no specific training was done to train the residents how to use the AAC devices, so this result was not unexpected.

We did find that of the six ACUs that received the training, only three showed use of the AAC devices afterward as measured in the observations by the research assistants.   This was of concern to us. However, in the concluding interview with the AD educator who conducted the trainings, we found that during her ongoing, frequent contacts with the ACUs she had observed use of the AAC devices in every ACU that had received training.

Aim 3: To determine differences in attitudes toward using AAC in ACU caregivers before and after the training. We thought that care providers would report that AAC use was more important after the training than they had thought it to be before the training.

What we found: This hypothesis was measured by the answer to two questions on the questionnaire that participants completed several times over the course of the project. The caregivers did not report that they thought AAC use was more important after the training; instead their attitude towards the importance of AAC remained the same over the duration of the project.   We believe that the wording of the questions influenced the participants to report that AAC use was very important to their interactions with the residents each time they were asked.

Aim 4: To determine if the trainings had any effect on the programs of the ACUs or on state policies in terms of requirements for licensed long-term care providers. We expected that new knowledge and awareness regarding the use of AAC might influence the policies of ACUs or state guidelines.

What we found: At the individual ACUs our expectation was not supported because, as reported by the administrators, the appropriate place for that kind of language would be in what is called a "disclosure document".   This document states to the family of a resident what the facility is committing to in terms of care and who will provide the care. It lets the family know what kinds of training the staff receives and how often they receive them. Training in communication techniques is already required by the state. Those ACUs that received the project's training can add to the disclosure document assurances to the family members that communication supports such as AAC will be used when they are appropriate. The administrators at the participating care facilities that we interviewed after the project said that

while AAC is not a mandatory part of the caregiver's job, they encourage them to communicate with their patients. The AAC devices are available and their use is supported.

With regard to the State of Oregon Administrative Rules for endorsement of Alzheimer's Care Units, no changes had been made related to AAC use at the time that this report was written. That is because no date had yet been set at the state level to rewrite these rules. However, Joyce Beedle, the AD educator for the project, has requested to be included in the rewrite and her request has been accepted. She intends to advocate for the inclusion of AAC training and use.

What do we do with what we have learned?

Joyce Beedle, the AD Educator for RUSH, spoke about the techniques used in this project to the Oregon State University 2008 Gerontology conference on Active Approaches to Healthy Aging and to the Oregon Health Care Association (OHCA) Conference 2008. In 2009 she planned to present techniques and results to the annual McGinty Memorial Conference on Alzheimer's disease. Most importantly, she has incorporated AAC training into her regular training activities with ACUs around Oregon.

Drs. Fried-Oken and Rowland, lead scientists for this project, discussed project results at the 2008 Biennial Conference of the International Society for Augmentative and Alternative Communication (ISAAC) in Montreal, Quebec in August, 2008.

Where do we go from here?

One conclusion of our research was that significant barriers to the use of AAC for dementia exist. This mirrors the barriers that have been documented for AAC use by children in schools.

The ACUs we visited varied greatly in size, in the quality of care they provided and in the enthusiasm of the administrators for the activities promoted by this project. Anecdotally, it was clear to us that the ACUs that really embraced the AAC use after training were those that enjoyed a strong initial "buy in" from the administrative level and provided continued administrative support for project participation. We could see that providing new knowledge is only the beginning. It needs to be paired with on-going administrative support and follow-up training.

We decided that our training would have been stronger if we had provided videotaped demonstrations of the use of AAC devices with adults who have dementia. We also found that many caregivers believed that only certain residents could benefit from AAC devices, and that these beliefs persisted despite information to the contrary. Adding videos of people with different levels of dementia using AAC devices to the curriculum would help solve this issue.

Feedback from the ACUs suggested they would be very interested in communication boards that had symbols for the daily needs of the residents, for example picture symbols that represent grooming or food-related information. The caregivers felt that boards with these kinds of photos would be used

much more often.   A consideration for a future project would be to select the vocabulary to be used for the AAC device with input from the caregivers.

An unanticipated and positive outcome of the training, reported by our AD Educator, was an elevation in staff self-esteem by virtue of their involvement in our research project. Nurse aides sometimes feel that they are the bottom rung of the employment ladder at ACUs. The fact that their opinions and help were valued as part of a scientific research endeavor involving state-of –the-art clinical strategies appeared to boost their confidence.

A next step might be to continue this training with families. Our AD Educator encouraged staff to tell families about the AAC devices. She told the staff that families should be encouraged to use the devices to help them reconnect with their family members. Often, family members don't know how to communicate with their loved ones who have dementia. Our curriculum, if adapted, might help family members and volunteers interact in more successful ways with people who have dementia. The state requires a monthly family support group at each ACU. A family-focused AAC training could be offered at one of these gatherings.