

RENAL REHABILITATION REPORT

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Rehabilitation and Employment

In the past, the term “rehabilitation” was often used synonymously with the concept of “vocational rehabilitation.” More recently, healthcare professionals have come to appreciate the fact that full rehabilitation addresses restoration of the body, mind, and spirit—a concept much bigger than employment alone.

To be able to work, people on dialysis must feel well, have sufficient energy, feel confident and equal to the task before them, and be at peace with limits and opportunities available to them, despite their kidney disease. These concepts are the essence of the Life Options renal rehabilitation perspective.

This issue of the *Renal Rehabilitation Report* explores some of the barriers to employment for dialysis patients. It discusses the important role of exercise, and outlines proposed legislation that has the potential to improve employment opportunities for people on dialysis. In addition, it introduces a new Life Options program, and includes other resources for renal patients and professionals who believe that full restoration is a worthy and achievable goal.

For more information about employment and renal rehabilitation, contact the Life Options Rehabilitation Resource Center (RRC) at (800) 468-7777.

DIALYSIS AND EMPLOYMENT Examining Issues, Exploring Ideas

In the few short decades since dialysis became an available treatment, much has changed regarding employment of people with end-stage renal disease (ESRD). Prior to 1972, the only patients selected to receive dialysis were those who demonstrated the greatest potential for rehabilitation—specifically, employment. Most of these candidates were younger, already established in the workforce, and had few or no comorbid conditions.

At that time, the expectation was that nearly everyone on dialysis would stay employed or return to the workforce with some amount of retraining.¹ Since continued treatment was perceived to be dependent, at least in part, on continued employment, expected and actual employment rates were very consistent.² In fact, 97% of all patients in one early home hemodialysis study were employed.³

The Medicare ESRD Program

When the Medicare ESRD program was established in 1972, these high employment rates began to decline. As dialysis became available to nearly all patients who needed it, the overall dialysis population became older, with reduced physical capacity, and more comorbid conditions. As a result, the number of employed dialysis patients declined dramatically, and has since hovered around 20%.

Over time, it became apparent that high employment rates were less realistic in a patient population that included older

patients and patients with a higher number of comorbid conditions. Healthcare providers began taking a more global approach—one that considered employment to be just one of many aspects of renal rehabilitation.

A Shift in Focus

While employment is not achievable for all people with ESRD, identifying those who have the potential for employment is a practical goal. Several recent studies have paved the way for doing just that. In one such study of patients age 18 to 59, only 11% were employed, yet one-third of those who were not employed reported feeling “able to work.”⁴ Similarly, while 24% of working age patients in another study were employed, 21% of those who were non-employed reported being both willing and able to work.⁵

There has been some disagreement about the exact factors that contribute to employment success for people on dialysis. However, research has suggested that such characteristics as a patient’s age, race, education level, health status, physical ability to perform job tasks, and recent work experience are associated with reported ability to work.⁴

For example, employment rates tend to be higher among patients who have somewhat more education, who are not diabetic, and whose employers are willing to adjust work schedules and requirements.⁴ With this information in mind, dialysis care providers have shifted to a new, more realistic focus—

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INCREASING PHYSICAL FUNCTIONING: Exercise Program Inspires Activity



At Dialysis Clinics Inc. (DCI) in Lee's Summit, MO, dialysis team members have seen a considerable increase in their patients' activity levels—an increase they believe has a lot to do with their in-unit exercise program.

“When you walk into our unit, you see patients engaging in physical activity—riding exercise bikes, talking, joking, laughing, and encouraging each other to do a little more,” describes dietitian Brad McElwee, MS, RD.

McElwee and the rest of the DCI staff are convinced that exercise can improve physical functioning for people on dialysis, and they pass this philosophy on to patients. “We encourage patients to give the bike a spin, or to ride a little further each day,” says McElwee. “Our goal is to motivate patients to forget what they feel they cannot do, and to show them what they can do to increase physical capacity and, ultimately, quality of life.”

Program Beginnings

DCI's exercise efforts are centered around an in-unit biking program, an idea that first came from renowned exercise physiologist Dr. Patricia Painter. “I saw a presentation by Dr. Painter,” says McElwee, “and I knew this was something I wanted to try in our unit.”

Dr. Painter's ideas were more than just a springboard for the DCI program. “We have

followed her guidelines and recommendations throughout the development of our program,” notes McElwee.

The Life Options *Exercise for the Dialysis Patient* series was also a good resource for DCI staff. “We cut out the individual strengthening exercises from the patient booklet and laminated each one,” explains McElwee. “That way, we could sit down with each participant, pick out specific exercises, and tailor a program for each patient's needs.”

About the Program

DCI's program follows a simple process. After patients receive written permission from their physicians and sign a consent form, they are eligible for participation. Generally, patients begin the cycling program with a 5-minute, low-intensity session, and add 1 minute each session thereafter.

“We like to have them start slowly and progress gradually,” says McElwee. “That way, we tend to avoid soreness that may prevent them from wanting to continue with the program.”

While the DCI staff has set a general program goal of 30 minutes of low-intensity biking per session, McElwee stresses that, ultimately, goals for duration are left to each patient. “Encouraging patients to have control over such aspects of their rehabilitation helps to foster a sense of independence,” he explains. “Most patients want to push their own limits. Several have worked up to 90 minutes per session, and a few have even chosen to cycle throughout their entire dialysis treatment.”

The Teamwork Approach

While it was McElwee who initiated the DCI program, he credits much of its success to teamwork. “One person can't do it alone,” says McElwee. “The whole unit has to work as a team—and the program rests on the

shoulders of those who work on the floor with the patients on a day-to-day basis.”

Indeed, support for the program has come from each level of the DCI staff. “Our administrator has always been a huge support,” says McElwee. “In addition, our unit has five nephrologists—and every one has backed the program from the beginning.”

Starting the program was not without its challenges, however. One of the biggest was overcoming the myth that exercise was dangerous for people on dialysis. In addition, there were also some concerns that the program would require a lot of additional work for staff who were already very busy.

With the help of several educational resources that addressed safety concerns, the program’s benefits soon became apparent. “We have also seen that the program hasn’t meant extra work for the staff,” says McElwee. “In fact, it

has meant less work in the long run, as patients have gained a sense of confidence and independence from their efforts. It has been very rewarding for patients and staff alike.”

Program Results Prove Positive

The DCI program has seen many other successes as well. “We have patients who have returned to the workforce and who have stimulated their bodies and minds to accomplish dreams,” says McElwee. “Many say they feel better both mentally and physically than they have in years.”

These observations are backed by physical assessments, which are regularly conducted by the DCI staff. In the first 6 months of the program, patients showed an average of 25% improvement over their baseline measurement on a 1-minute sit-to-stand test—an increase that has been maintained over the last 2 years.

According to McElwee, these improvements in physical functioning have led to positive changes in patients’ overall quality of life. “One woman began our program with one goal: to be able to bowl again,” explains McElwee.

“Less than 6 months after beginning the exercise program, she was able to rejoin her old bowling league,” he says. “It is this kind of success—helping patients to realize their personal goals—that is so gratifying.”

Sharing Successes

DCI’s exercise program has been successful on many levels, and has been rewarding for patients and staff members alike. Says McElwee, “It’s the best part of my job.”

The program is now in place at four DCI units in Missouri, including Lee’s Summit, and plans call for its expansion to a fifth unit in the near future. ♦

Improving Physical Functioning: An Exercise Case Study

Adam, a 76-year-old hemodialysis patient, has participated in DCI’s exercise program since October 1997. Before he began the program, he experienced problems with fatigue and relied on his wife to help with many daily activities. “I would get tired from just walking down the driveway to get the newspaper,” he reports.

Adam began DCI’s exercise program with 6 minutes of very low-intensity biking and increased his time by 1 minute per treatment session. He now bikes for 90 minutes each time he dialyzes.

As with other patients in the DCI program, improvements in Adam’s physical functioning have been noted on the 1-minute sit-to-stand test. These improvements have translated into positive changes in his daily routine.

“Adam is much more active now than when he started the program,” says his wife. “He does a lot of lawn work, he can walk around the

whole department store or grocery store without resting, and he can play with our grandson without having to sit down.”

In addition to the positive changes in his lifestyle, the biking program has made a difference in the unit as well. “Adam has become a very positive influence for the other patients and is self-sufficient with regard to his own care,” says nurse manager Jodi Oglesby, RN, CNN.

Other staff members agree. “Adam is the model patient,” adds charge nurse Pat Barnett, BSRN, CNN. “He comes in happy, we give him his bike, he bikes, and then he pushes the bike away and reclines himself. He rarely has complaints.”

Outside the unit, Adam’s activities include holding elected positions in two retirement organizations. “I know that biking is good for me,” he says. “It makes me feel good, it makes the time go faster, and I will continue to do it every time I do dialysis. I am in good shape even though my kidneys are not.”

EMPLOYMENT AND ACTIVITY:

Active Engagement Benefits People on Dialysis

I have always found it important to have goals to work toward,” says dialysis patient Karen Davis. “So, once I began to feel better, I decided that I wanted to return to an active role in society.” For Davis and many other people on dialysis, a return to productive activity means a return to work.

Davis was 47 years old when she began peritoneal dialysis nearly 4 years ago. After taking some time away from work while her health stabilized, her own strong self-motivation and her medical team’s support led her to return to her job as an administrative assistant 25 hours a week. “[My doctors] wrote letters to my employer, stating that the only accommodation I would need would be a part-time schedule due to dialysis.” Davis now works weekdays from noon to 5:00 pm and dialyzes overnight.

Remaining Active

For many people like Davis, once the clinical prerequisites of anemia control, adequate dialysis, good vascular access, and proper nutrition are in place, employment and other meaningful activities can offer many benefits. Remaining engaged in life through such activities is a key to minimizing the debilitation, depression, and detachment from society that often accompany a chronic illness such as end-stage renal disease (ESRD).¹

There are many activities that can aid in the rehabilitation process for people on dialysis. For example, as shown on pages 2-3, patients who keep fit through exercise are more likely to seek or maintain employment or volunteer work, and to enjoy hobbies, travel, family and social activities.² Employment—whether it is full- or part-time, permanent or temporary—can also have many clinical, social, and financial benefits for those who are willing and able to work.²

Most people on dialysis face financial concerns related to their treatment. Working can help

reduce many of these concerns. For instance, group health insurance, which is available through many employers, may help cover certain treatment-related expenses that are not covered by Medicare. In addition, working patients may more readily afford such things as the renal diet, adequate transportation, safer neighborhoods, and entertainment.

“...once I began to feel better, I decided that I wanted to return to an active role in society.”

—Karen Davis

Additional Benefits

Aside from the financial advantages, employment can offer many additional benefits for people on dialysis. For example, more than 80% of working patients in a recent study reported that they enjoyed their work and benefited from their jobs. Most felt that performing well at their job made them feel worthwhile.³ In addition, working patients more often participated in community activities, and reported higher self-esteem and quality of life than unemployed patients.⁴

Another study showed that active involvement in life may actually help patients live longer. Employed patients scored higher than their non-employed counterparts on measures of medical, psychological, and social adaptation⁴—factors that help to predict survival among dialysis patients.^{5,6} “Returning to work helped give me a purpose and a direction,” agrees Davis. “It enhanced my mental and physical outlook, and it gave me something to do besides thinking about being on dialysis.”

Dialysis facilities also benefit when patients are employed or otherwise actively engaged

in life. For example, patients who are involved in community activities report lower treatment stresses, and those who are working have significantly better relationships with dialysis personnel and other dialysis patients.⁴

In addition, employment has been associated with improved adherence to dialysis treatment plans. Specifically, patients who work may have fewer avoidance behaviors that could lead to compliance problems.⁴ Since missing work or appearing unproductive could jeopardize a job, most working patients are also highly motivated to stay as healthy as possible.

Finally, when employed dialysis patients are encouraged to share their successes with other patients, they can have a positive effect on the overall morale of the facility. Many dialysis professionals report that working with patients who are actively engaged in work or other activities is especially rewarding.

For patients who are willing and able to work, the benefits of employment cannot be underestimated. Davis agrees. “I tell other patients not to lose heart—that having outside contacts and interests can improve their quality of life, and that they can get back to a normal routine, even with dialysis.” ♦

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WORK INCENTIVES IMPROVEMENT ACT:

New Work Incentives Bill Now Under Consideration

A new bill that may have positive implications for people on dialysis is now being considered by the United States Senate. The bill, called the Work Incentives Improvement Act of 1999 (S.331), was recently introduced by Senators James Jeffords, Edward Kennedy, William V. Roth, Jr., and Daniel P. Moynihan, and is supported by President Bill Clinton and a bipartisan group of senators. The companion bill (HR.1180) has also now been introduced in the U.S. House of Representatives.

In general, the bill is designed to amend the current Social Security Act to expand the availability of healthcare coverage for working individuals with disabilities, and to provide disabled persons with meaningful opportunities to work.

About the Bill

One of the main provisions of the bill, the *Ticket to Work and Self-Sufficiency Program* (TWSSP), proposes to establish a new payment system designed to provide greater choice to persons with disabilities seeking assistance with vocational assessment, training, and placement. The TWSSP would establish a system under which disabled persons could be issued a "ticket" to obtain help in becoming

employed. According to a customized work plan, these tickets could be used to help individuals obtain employment services, vocational rehabilitation services, or other support services from a participating, approved public or private employment network.

Other Work Incentives Improvement Act provisions that have the greatest potential to help people on dialysis include:

- An allowance for working persons with disabilities whose income is over states' guidelines to buy into Medicaid on a sliding scale, depending on their income
- Introduction of a trial program to extend Medicare coverage from 39 months to 10 years for Social Security Disability Insurance (SSDI) beneficiaries who return to work. This could provide an incentive for dialysis patients to seek transplant, or for transplant patients to seek work.
- Support of states' applications for demonstration projects to test innovations for promoting employment of persons with severe disabilities
- Expediting the reinstatement of disability benefits for individuals whose employment efforts are not successful

- Development of outreach and assistance programs to help persons with disabilities understand work incentives

In addition to these provisions, Congress has asked that a report be completed after 8 years to summarize how effective the work incentives program has been at getting persons with disabilities back to work.

Additional Proposals

The President and the Senate have also proposed several other initiatives that may assist people on dialysis. Current recommendations include a \$1,000 tax credit to help the disabled cover work-related expenses, including special transportation, and a \$35 million grant to develop technology that will aid disabled persons' participation in the workforce.

For More Information

For more information about the Work Incentives Improvement Act, contact the Life Options Rehabilitation Resource Center (RRC) at (800)468-7777. A brief summary of the bill can also be found at the following website: <http://thomas.loc.gov>. ♦

NKF Releases RISE Program

After several years of planning, the National Kidney Foundation (NKF) is ready to launch its Rehabilitation, Information, Support, and Empowerment (RISE) program. Funded by an educational grant from Amgen Inc., RISE is based largely upon the NKF of Michigan's highly successful OUTREACH rehabilitation program.

RISE is designed to help individuals with kidney disease return to meaningful activity, including resuming daily activities, employment, continuing education, and volunteerism. The program also provides information about the importance of adequate treatment, and emphasizes physical fitness—both of which are important to successful

renal rehabilitation. In addition, for those who have never been in the workforce, or who are returning after a long time away, the program provides experience in basic employment skills and informs individuals of their legal rights in the workplace.

The comprehensive 4-day RISE program focuses on the following topics: "Taking Charge," "Rights and Responsibilities," "Making Your Skills Work for You," and "Developing a Plan and Support for You."

For more information about the RISE program or about other NKF initiatives in renal rehabilitation, contact the NKF at (800)622-9010.

DIALYSIS AND EMPLOYMENT:

Examining Issues, Exploring Ideas (continued from page 1)

helping work-willing and able patients maintain their employment early in the course of their treatment rather than trying to achieve re-employment later on.

Barriers to Employment

While great strides have been made in identifying patients who are most likely to achieve vocational rehabilitation, real and perceived barriers to employment remain. Some of these barriers include the following:

Fatigue

For people on dialysis, the effects of uremia and related problems can greatly reduce their level of physical functioning. A minimal level of fitness is required for even the most sedentary work. Dialysis patients with chronic anemia may feel too fatigued for normal activity—or for pursuing rehabilitation goals such as employment. While improved dialysis technology and EPO have allowed many patients to be more active, matching physical functioning with vocational goals remains a priority.

In addition, once clinical considerations are addressed and patients are medically stable, exercise helps to improve physical functioning, which can promote better mental health and emotional well-being.⁶ Exercise also helps empower patients to test the limits of their environment and engage in activities, including work, that they might otherwise be reluctant to attempt.⁷

Financial and Health Concerns

Financial concerns are common among many people, including those on dialysis. Many renal patients on disability fear that a return to work will result in a loss of benefits. This does not have to be the case. People on dialysis may be eligible for various employer and government programs that help people with disabilities maintain employment. For example, employers may have group insurance

that can help pay for the costs of treatment and medications not covered by Medicare.

In addition, Social Security Disability Insurance (SSDI) allows those with an employment history to work and still receive disability checks for 9 trial work months in a rolling 5-year period. Any month in which \$200 or more is earned is a trial work month. After all trial work months are used, disabled persons can receive SSDI benefits if their monthly earnings are less than \$500 (\$700 as of July 1, 1999).

For patients with low income and little or no employment history, a Supplemental Security Income (SSI) work incentive program called Section 1619 lets recipients keep all earnings. Under this program, a patient's SSI check is reduced \$1 for every \$2 earned, and Medicaid coverage continues. (For information about other work incentives under consideration, see page 5.)

In addition to financial concerns, many people on dialysis fear that working will harm their health. On the contrary, employment has been shown to improve physical and emotional well-being for people on dialysis,⁸ and may offer substantial economic benefits to patients, families, and society. (For more information about the benefits of employment, see page 4.)

Fear of Discrimination

Research has shown that dialysis patients' employers and family members have a great deal of influence on employment potential. Not surprisingly, patients who believe their family and dialysis team support their decision to work are more likely to be employed.⁵

With this in mind, the perceived potential for workplace discrimination is a special concern for people on dialysis. Patients may worry that their employers will have negative beliefs about their productivity and ability to work.

Fortunately, several recent studies help to address such beliefs.

For example, in the first 6 months after returning to work, more than half of the dialysis patients in one study had not missed a day due to illness.⁹ In general, absenteeism among disabled workers was the same as or less than average in 95% of cases, and disabled workers had average or better productivity in 91% of cases.⁹

Need for Accommodations

In some cases, patients do not return to work because they need accommodations and fear their employer will not be willing to provide them.¹⁰ However, even before the Americans with Disabilities Act was passed, one study found that two-thirds of working patients had employers who made accommodations for their illness.¹⁰ Such accommodations included adjusting work hours, allowing more breaks, shortening the work day, and adjusting job responsibilities.

Another study found that 50% of workplace accommodations required for disabled employees were free, and an additional 30% cost less than \$500.⁹ In many cases, state Offices of Vocational Rehabilitation (VR) can help pay for some of these expenses.

Overcoming Barriers

The Life Options publication *Building Quality of Life: A Practical Guide to Renal Rehabilitation* offers the following suggestions for dialysis care providers interested in helping patients keep their jobs or return to work:

- Reassure new, working-age dialysis patients that they will feel better once they are no longer severely uremic.
- Recommend that new patients consider a brief period of disability, if necessary, rather than quitting their jobs and losing

income, health insurance benefits, and self-esteem.

- Assure patients that Medicare benefits (once begun) are related to their kidney failure, not to disability. Working will not jeopardize these medical benefits for people on dialysis.
- Offer to contact the employer (at the patient's discretion) to explain kidney failure and its effects. Overcoming employer misconceptions can go a long way toward building positive support from a supervisor.
- If necessary, investigate possible work/school accommodations with the local Office of Vocational Rehabilitation. Patients may be covered under the Americans with Disabilities Act, which requires "reasonable accommodations"

that may include seating, extra breaks, flexibility in scheduling, or a clean room and time to perform PD exchanges.

Looking to the Future

In the past, "rehabilitation" was often equated with employment alone. However, healthcare providers have come to view employment as just one of many aspects of renal rehabilitation.

Despite this more global approach, vocational rehabilitation remains an important goal for people who are willing and able to work. As such, identifying factors that lead to employment success and addressing barriers to employment continues to be of primary importance. ♦

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More Information About Employment

Life Options Employment Resources

An updated version of *Employment: A Guide to Work, Insurance, and Finance for People on Dialysis* is now available for dialysis patients and professionals who want to know more about employment and related financial issues.

The booklet includes updated information on employment and insurance options, and other services and benefits available for people with end-stage renal disease (ESRD). It features ESRD patients who are successfully employed, taking classes to update their skills, or engaged in other rehabilitation activities. The booklet also provides the latest information on:

- Employment issues and tips for individuals with ESRD
- Vocational rehabilitation services
- Disability programs, including Social Security
- Work incentive programs
- Medicaid
- Pertinent legislation, such as the Individuals with Disabilities Education Act (IDEA)

- An expanded, comprehensive list of renal rehabilitation resources and publications, including websites

Employment: A Guide to Work, Insurance, and Finance for People on Dialysis is available free of charge from the Life Options Rehabilitation Resource Center (RRC) at (800)468-7777.

NKF Employment Resources

The National Kidney Foundation (NKF) has also released a new series of 12 brochures designed to enhance the rehabilitation potential of people with ESRD. The series, *Kidney Disease and Rehabilitation*, features valuable information on all aspects of renal rehabilitation.

Publications focusing on employment include *Facts About Kidney Failure: A Guide for Employers*, which is designed to provide information about ESRD and encourage employers to hire people with ESRD, and *The Role of the Rehabilitation Counselor*, which is designed to assist professionals in working with patients toward the goal of rehabilitation. *Kidney Disease and Rehabilitation* can be ordered by calling the NKF at (800)622-9010.

KEYS TO A LONG LIFE

LIFE OPTIONS RELEASES NEW PROGRAM:

New Resources Focus on “Keys to a Long Life”

People with end-stage renal disease (ESRD) *can* live long and live well on dialysis. This is the core message of the exciting, new Life Options *Keys to a Long Life* patient materials. These free educational tools are designed to motivate people on dialysis and teach them how to optimize their dialysis care and improve their quality of life.

Keys to a Long Life Materials

Living with Dialysis: Getting the Most Out of Life is a 40-minute video directed toward people on dialysis. Six patients highlight the “keys” behind their successful rehabilitation—their tips and techniques for living long and well on dialysis. Even the narrator is a long-term patient.

From how to communicate with the nephrologist, to education and self-advocacy, these patients share their unique and valuable perspectives with viewers. Because it is made up of five stand-alone segments, this video can be watched all at once or a little at a time.

A 90-minute audiotape, *Voices of Experience: Personal Stories of Living with Dialysis*, features an in-depth conversation with four long-term dialysis patients who are living full and productive lives in spite of ESRD. In their own words, Mike, Nancy, Stan, and Kathy emphasize the importance of learning about dialysis, taking an active part in treatment, and having a positive attitude.

Other *Keys to a Long Life* materials include:

- A full-color poster featuring five active people who have more than 100 combined years on dialysis
- Four Patient Interest Checklists to help staff and patients find and address knowledge gaps
- A Goal-setting Worksheet to help patients determine and achieve their goals
- Six easy-to-read Fact Sheets for patients that address clinical and rehabilitation topics
- A Staff Idea Guide with detailed descriptions of the *Keys* products and tips for their use

New Video for Nephrologists

For the Nephrologist: Caring for People with Kidney Failure is an 11-minute video for physicians, narrated by Christopher Blagg, MD, nationally-renowned nephrologist from Seattle, WA.

Dr. Blagg advises physicians that it is vital to include patients as partners in the medical decisions that affect their care and their lives, and suggests strategies for working with patients. Dialysis patients also give tips for communicating with physicians and taking a proactive approach to get their needs met.

Order Your Copy Today

Professionals who work with dialysis patients can order the complete set of *Keys to a Long Life* products—or any part of it—free of charge. Dialysis patients can order the Checklists, Fact Sheets, and Goal-setting Worksheets. For more information, contact the Life Options Rehabilitation Resource Center (RRC) at (800)468-7777. ♦



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The Renal Rehabilitation Report is dedicated to identifying effective programs, projects, and people who are helping dialysis patients realize their fullest potential.

RRR is a bimonthly publication of the Life Options program, which supports initiatives for renal rehabilitation in the vital areas of Encouragement, Education, Exercise, Employment, and Evaluation.