Life Options
CELEBRATING 10 years
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Nephrology News & Issues
Tomorrow's Answers Today

The Unit Self-Assessment Tool

Setting the Benchmarks for Progress and Change

Since its inception in 1993, Life Options has followed a two-pronged, research and response approach to rehabilitation. On one hand, Life Options derives definitions, develops theory, and addresses key questions through research.

And on the other, Life Options develops practical, no-nonsense tools for clinicians to use themselves and to help educate their patients. The *Unit Self-Assessment Tool* (*USAT*)[1] is a perfect example of this unique approach.

DEFINING MOMENTS

In 1993, Life Options identified five core components of rehabilitation—Encouragement, Education, Exercise, Employment, and Evaluation. This "5 E's" framework became the foundation for thinking about rehabilitation in concrete terms—the first step toward actively doing rehabilitation activities.

But what are rehabilitation activities? Traditionally, only vocational rehabilitation was considered—but there were 5 E's to embrace, not just one.

The Life Options Rehabilitation Advisory Council (LORAC) devised an ingenious way to identify rehab activities—while at the same time honoring individuals and groups who were innovative enough to begin rehabilitation programs, and creating a forum for sharing new ideas. They held a contest.

Over the next 4 years (1994–1997), more than 150 organizations and facilities submitted entries for the annual Life Options *Exemplary Practices in Renal Rehabilitation* competitions, detailing their rehab programs and activities. (See the article on pages S8–9 and this month's Q&A for an interview with an *Exemplary Practices* winner.)

(continued on page S10)

Message from the LORAC Chair

Only a rare few dialysis centers were even talking about rehabilitation in 1993, when Life Options was founded. Ten years later, in 2003, we have arrived at a point where the relationship between rehab and quality of life is almost universally recognized.

Why did this enormous transformation take place? In part, it has been a result of Life Options persistent and focused attention on the pressing need for rehab programs and their tremendous potential to improve quality of life.

How did it happen? With practical guidance from Life Options. Not only did Life Options provide a conceptual framework—the "5 E's"—for thinking about rehab; Life Options also created the tools to help providers take action.

The Life Options commitment towards putting theory into practice has been the driving force behind the development of practical ways to measure rehabilitation, plan interventions, and evaluate progress. It is immensely gratifying to see these practical tools being used, and producing results.

It is encouraging to know that data from these real-world experiences will enable Life Options to refine and expand on recommendations for helping people with kidney disease live long and live well.

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RENAL REHABILITATION REPORT

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Rehabilitation in Action

Using the *Unit Self-Assessment Tool* for CQI

Over the last decade, some rehabilitation questions have been answered—and many more have been raised. For example, what are the best ways to approach rehabilitation? Which rehab activities can be measured? And, how can we prove that rehab really works?

Several years ago, with these questions in mind, Life Options developed the *Unit Self-Assessment Tool* (*USAT*). Today, many organizations—including ESRD Network 6 and Renal Care Group (RCG)—are using the *USAT* to collect rehabilitation CQI data and improve patient outcomes.

NETWORK 6

As part of their contracts with CMS, all ESRD Networks have been charged with the goal of enhancing vocational rehabilitation. Network 6, covering Georgia, North Carolina, and South Carolina, has taken rehabilitation one step further.

"After reading the various Life Options materials, we decided not to focus on one area alone," says Ann Lefebvre MSW, Network 6 Patient Services Coordinator. "We wanted to promote the full idea of rehabilitation, but we needed to decide where to start. That's where the *USAT* came in."

In January 2002, Network 6 distributed the *USAT* to all of its dialysis centers—a total of 392, serving approximately 26,000 patients. "We sent letters to each unit outlining how the *USAT* data would be used," Lefebvre says. "We wanted them to understand how important this was."

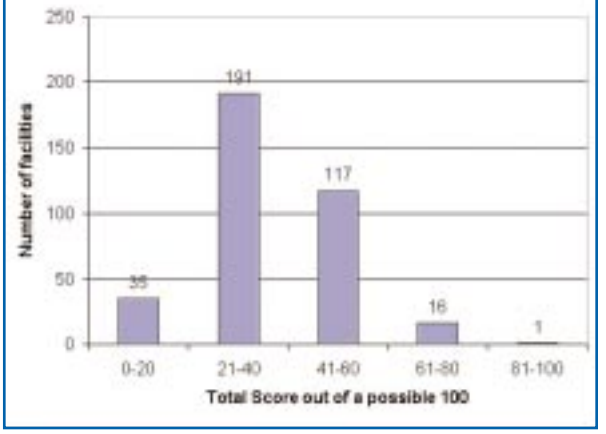
By March, a remarkable 92% of the units had responded, providing the Network with some valuable information. "We started this project with the idea that rehab was a component in ESRD that needed attention," says Lefebvre. "The *USAT* data seemed to confirm that."

After their initial assessment was complete (see chart below), Network 6 followed-up with an information campaign. "We sent quarterly packets to each unit," Lefebvre explains. "Each contained information about a specific 'E' category, along with a letter explaining how to use the materials."

This summer, Network 6 will readminister the *USAT* to determine the effectiveness of this initiative. Preliminary reports from the field have been promising. "The social workers I've talked to have been very positive," she explains. "They like hands-on materials they can use with patients."

For facilities thinking about using the *USAT*, Lefebvre offers the following advice. "You don't have to reinvent the wheel," she says. "With Life Options, all the materials are available on-line—and everything follows the *USAT*, step-by-step. It's a complete package and a valuable tool."

ESRD Network 6: USAT Rehabilitation Total Scores



RENAL CARE GROUP

With more than 260 outpatient dialysis centers, in addition to providing acute dialysis services at 120 hospitals, serving 20,500 patients in 27 states, RCG looked to the *USAT* to provide a "macro" perspective. "We wanted to know more about what was happening company-wide, in terms of rehab," says RCG patient services manager and Life Options Council member Wendy Funk Schrag, LMSW, ACSW. "We had heard about the results of the Texas-*USAT* Renal Rehabilitation Study, so we thought we'd give it a try here."

In 2001, RCG took the first step, by e-mailing the *USAT* to social workers in each of their centers. "We encouraged them to complete the assessment as a multidisciplinary team," explains Schrag. "We felt that would give us the best overall view of what was going on."

After their initial assessment, RCG followed up by phone with the centers that scored highest in each *USAT* category. "We wanted to ask them more in-depth questions about their programs," explains Schrag. "For us, that was the fun part. We found a lot of enthusiasm out there—and we learned a lot."

RCG has put this information to good use. In the last year, they created a new position for a Patient Rehabilitation Director. Under the direction of a new Rehabilitation Advisory Board, RCG is now developing a rehab manual for center staff. They are also working on an incentive program to reward unit progress in each of the five "E" categories.

RCG readministered the *USAT* in 2002, with interesting results. "We saw the biggest increase in the area of Evaluation," says Schrag. "We also saw that regions that were less spread out geographically had higher scores."

According to Schrag, RCG plans to continue with yearly rehab assessments. "We're not just measuring what's going on now," she says. "We're trying to put the data to use—to implement CQI and make improvements." ◆

The *Unit Self-Assessment Tool* is Available On-line!

To assess rehabilitation programming in your center, order a copy of Life Options *Unit Self-Assessment Tool for Renal Rehabilitation* (*USAT*). Print copies are available from the Rehabilitation Resource Center—to order, call (800) 468-7777 or download a copy from the "Free Materials" section on the professional side of the Life Options website (*www.lifeoptions.org*).

The *USAT* categorizes 20 rehabilitation activities into basic, intermediate, and advanced levels within each of the 5 E's. Each activity is worth one point, for a possible total of 100 points (for more information about the *USAT*, see the lead story on page S1.). Sample *USAT* questions at every level within the five "E" categories are featured below:

Encouragement:
Do you have a centrally located bulletin board featuring patients who actively pursue rehabilitation?
Do you have patient support groups that are run by a facilitator?
Do you track the costs associated with your encouragement-related activities and programs?

Education:
Do you have a special orientation program for new patients?
Do you hold any in-unit educational sessions or programs?
Do you have regular/periodic educational sessions in which patients can participate?

Exercise:
Do you provide information or make referrals to community exercise resources?
Do you have any fitness apparatus or exercise equipment available at the unit?
Do you track the outcomes or results of your exercise-related efforts?

Employment:
Do you inform patients about choice of treatment modalities to accommodate their work and life interests?
Does your unit automatically refer all working-age patients to vocational rehabilitation?
Do you provide any early interventions (predialysis or within first 6 weeks) to help patients keep their jobs?

Evaluation:
Do you perform regular assessment of patients' activities of daily living (ADL) status?
Do you perform formal rehabilitation intake assessments of new patients using standardized instruments?
Do you require periodic in-center progress evaluations by related services (PT, Dietitian, VR, Nephrologist)? ◆

Alpha Exams

Rehabilitation in Action: A New Model

What if patients could get individualized rehab care at their dialysis centers at no cost to them—or to the center? This is possible today in Houston, Texas, at Alpha Exams.

When it comes to the benefits of integrated rehabilitation programming, Debra Hill, LMSW-ACP, says the results speak for themselves. "Dialysis is hard on the body," she explains. "A coordinated rehab program, including exercise, can help counteract the deconditioning of kidney disease and dialysis. It can go a long way toward improving patients' quality of life—toward allowing them to do the things they want to do."

"Twenty years on dialysis doesn't happen by accident. You have to do something to make it happen—you have to work at it."
—Debra Hill

Hill is program director for Alpha Exams, a Medicare and Medicaid-approved ancillary healthcare services provider, based in Houston, Texas. Through a unique initiative, called the Renal Rehabilitation Program (RRP), Alpha Exams provides in-unit rehab services, at no direct cost to participating dialysis facilities, because they bill Medicare directly.

According to Hill, the idea for the RRP came about several years ago under the direction of Alpha Exams' president, Allen Goodlow, and medical director, Herbert Watkins. "At that point, we all knew about the benefits of rehabilitation," explains Hill. "But, for a variety of reasons, rehab programming really hadn't been implemented in a coordinated way." By 2000, the RRP had begun to change all that.

"5 E's" Framework

Today, the 14-member RRP staff includes a medical director, a physician's assistant, a registered nurse, several physical therapy technicians and clinical social workers, and a billing clerk. Together, the team delivers a stand-alone rehab program that is grounded in the Life Options 5 E's—Encouragement, Education, Exercise, Employment, and Evaluation.

According to Hill, the RRP concept is simple. "First, we talk with unit administration about how the program can benefit their patients," she explains. "After getting facility approval, we provide an orientation and begin talking with patients individually. For patients who express an interest, our next step is getting consent from the nephrologist."

The RRP team then conducts physical and psychological assessments to gather baseline data and develop treatment plans. Education and self-management are emphasized throughout the RRP; an in-unit exercise program includes range of motion, cycling, massage, and other activities that can be completed as patients dialyze.

In addition, a psychotherapy component supplements the work of unit social workers. "We concentrate on adjustment to illness," says Hill. "For patients, this includes staying active, getting back to work, even getting a transplant, if that's a goal for them."

Promising Results

The RRP is currently being implemented in three Houston-area dialysis units, with much success. "Typically, between one-third and one-half of the patients participate," says Hill. "Right now, there are 96 patients in the program."

For RRP participants, the rewards have been both physical and psychological. "Many patients report feeling stronger," Hill explains. "They are able to handle treatment better, they are not as depressed, and they have fewer absences. They are becoming more active in the treatment plan in general."

There are other, more long-term benefits as well. "Several patients are getting transplants and we're helping them work through those issues," Hill says. "Many patients are looking towards employment, when they never thought they would."

When it comes to rehabilitation, Hill says the bottom line is simple. "Twenty years on dialysis doesn't happen by accident," she explains. "You have to do something to make it happen—you have to work at it." The RRP is helping patients do just that. ◆

For more information about Alpha Exams *contact Allen Goodlow by phone at (713) 779-3661, by fax at (713) 779-3631, or by e-mail at a6414ag@aol.com.*

Revisiting an Exemplary Practices Award Winner

Dialysis Center of Lincoln Continues its Tradition of Excellence

"It's important for new patients to see they can still live life and still live their dreams."
—Ann Stivers

In 1995, the Dialysis Center of Lincoln (DCL) in Lincoln, Nebraska, won two awards in the Life Options *Exemplary Practices in Renal Rehabilitation* competition—one for Exercise and one for General Excellence. According to CEO Ann Stivers, many things have changed since then, but DCL's commitment to rehabilitation has never wavered.

In 1997, rapid growth spurred DCL's move to a new facility. Today, they serve 260 patients between their main unit, three satellite units, and five acute care programs. Even with such tremendous growth, DCL has found ways to build on the success of its award-winning program.

EDUCATION

As in 1995, education remains the cornerstone at DCL. All new patients and staff members receive information about all aspects of rehabilitation. DCL encourages staff members to attend local and national conferences by paying both time and expenses.

In addition to full-day predialysis education classes for new patients and families, DCL provides monthly teaching modules to address dialysis and life issues, ranging from holiday stress to infection control. A diabetes-certified facility, DCL now employs three diabetes educators.

Most recently, they have added computer outlets in the lobby to provide patients with Internet access.

DCL's effort to educate continues beyond facility walls. Four years ago they developed public service announcements for radio and television to help educate the general public about kidney disease.

"It has taken years and a lot of hard work, but we're finally beginning to see an effect," Stivers says. "Primary care physicians are referring to nephrologists earlier on, and many of our patients are now coming in with mature accesses."

ENCOURAGEMENT

As part of their encouragement efforts, DCL has added an ecumenical pastor—not to preach, but to offer support. They've continued a recognition program to honor birthdays and other important occasions, and their activities committee plans monthly events for patients and staff.

"As part of our predialysis orientation, we also bring in patients who have been successful in managing their kidney disease," she says. "It's important for new patients to see they can still live life and fulfill many of their dreams."

Q&A ASK THE EXPERTS: EXEMPLARY PRACTICES 8 YEARS LATER

An Interview with Ann Stivers, RN
CEO, Dialysis Center of Lincoln (DCL), Lincoln, Nebraska

Q *What was going on in rehabilitation 10 years ago, before Life Options?*

A When I first started in dialysis, the scope of activity was very limited for patients. They spent hours on the machine, with nothing really to do besides watch television. At that time, the purpose of dialysis was to keep people alive, period. I don't remember much discussion about quality of life. That was in 1987.

Q *What was DCL doing with rehabilitation before Life Options?*

A In 1990, we began implementing rehab on our own. We started small, with basic things. We held a yearly picnic for patients and staff. We went to patients' homes after work to sing carols during Christmas. We celebrated birthdays and other milestones.

At that time, the idea of an in-unit exercise program was still foreign to us. But, the bottom line was, we wanted to do more to help patients. So, we began developing a model of care that told them, 'You matter—your life matters.'

Q *What impact did Life Options have initially?*

A From very early on, Life Options helped to validate what we had started. That, in turn, allowed us to take off and build on our early ideas. Of course, Life Options also put the spotlight on exercise. For us, and for many others, that proved to be very important.

After hearing a presentation by Trish Painter, our dietitian came back very impressed with the idea of starting an in-unit bicycle program. So, after talking to our medical director, we bought several bikes and developed one of the first programs in the country.

Q *How has rehabilitation changed in the renal community over the last decade?*

A Rehabilitation really has come a long way. I used to talk with doctors who would say, 'Rehab is nice, if you can afford it. But I can't afford it.' And that would be the end of the conversation.

EXERCISE

DCL's exercise program is currently being revitalized under the direction of a new staff member. "We are just beginning to evaluate the number of patients in wheelchairs," says Stivers. "Aside from those with amputations and those who are paralyzed, this is a perfect opportunity to intervene with exercise."

Currently, about 25% of all DCL patients participate in the bicycle program, and nearly 40% total are involved in some form of exercise activity.

EMPLOYMENT

As part of their philosophy to support employment, DCL now offers evening shifts, even in the smallest of their satellite units. "In 1995, we encouraged people to maintain employment," says Stivers. "Now, we make the extra effort to accommodate work changes—we fit patients' dialysis schedules around their job schedules."

EVALUATION

As part of an extensive evaluation program, DCL now administers the SF-36 twice a year. They also publish the results of biannual patient satisfaction surveys. "If areas of concern are identified, we hold a patient meeting to discuss them," says Stivers. "That has been very helpful—it shows patients that we care what they think."

At DCL, evaluation goes a step further. "Not every patient will want to learn to put their own needles in, and that's okay," says Stivers. "But, do they know their lab values and how to improve them? Do they know how to get to dialysis if there is a snowstorm? That's part of evaluation as well. We continue to be involved in beta testing of new products and technology that will help improve the quality of care we wish to deliver"

OUTCOMES

The successes of DCL's rehabilitation program are reflected in their patient outcomes. DCL morbidity, mortality, and staff turnover rates remain below the national average, and they have above-average rates for transplant.

But Stivers likes to look beyond the numbers as well. "To see patients smile and strive to reach a goal they have and not feel that kidney disease is the end—that is where the reward is," she says. "This is not a job that becomes routine and boring. It's a chance to make a difference." ◆

Of course, there were people who thought the whole concept of renal rehabilitation was somewhat 'cushy.' But, over the years, it has become increasingly apparent that rehab is not just a 'nice' thing—that it can impact morbidity and mortality, that it can have a positive effect on the bottom line.

I think rehab really has become an accepted standard of excellence. It's good for patients, and it's good for the community of dialysis. The challenge now is to keep it going, especially with today's financial pressures and higher turnover rates among staff.

Q *What can be done to help overcome those challenges?*

A I don't think there's an easy answer. In our own unit, we have made rehabilitation a priority. I continually look to our data. What are our mortality and morbidity rates? What do our SF-36 scores look like? And, how does our rehab program impact on these things? We are always looking for ways to reduce costs while maintaining what is near and dear—the quality, the value-added services like those in our rehab program.

Q *How has rehabilitation changed at DCL since you won the Exemplary Practices in Renal Rehabilitation competition?*

A While we have continued to refine our overall program (see the story above for more information), our underlying philosophy has not changed. Over the years, I have asked my staff on many occasions, 'What is our purpose? What do we do differently?'

In my mind, our purpose is not simply to give dialysis—to bring people in and ship them out as quickly as possible. If we can do more than that—if we can provide patients with activities and education, keep them physically active, spend time talking to them—then, what we're really trying to do is to help them find meaning in life. Our purpose is to help patients find meaning in their lives while they receive dialysis.

I don't care if you're 20 or 80—everyone has dreams. Kidney disease and dialysis does not mean the end of those dreams. Life Options articulates this. They provide structure and a guide. They give us all something to strive for. There's a difference between existing with kidney disease and learning to live with kidney disease, and that's Life Options. ◆

The Unit Self-Assessment Tool

Setting the Benchmarks for Progress and Change

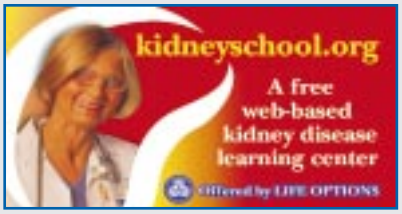
(continued from page S1)

BIRTH OF THE *USAT*

After organizing and cataloging all of the activities, Life Options developed the *USAT*: a comprehensive "report card" of 20 benchmark rehabilitation activities in each of the 5 E's categories, for a total of 100 items, each worth one point.

The *USAT* was the epitome of practical application. Individuals and centers that wanted to do rehab could choose activities from the *USAT* "menu" that best suited their financial situation, patient population, and patient needs.

Another practical use came to mind as well: the *USAT* could be used as a CQI tool—a checklist to assess ongoing progress toward rehab goals. Comparisons of a center's scores in one or more of the 5 E's areas could be made over time, or with a number of different centers.



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Life Options Rehabilitation Program
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414 D'Onofrio Drive, Suite 200
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The cost is $12 for 100 cards and $9.50 for each additional 100 ordered at the same time. Wisconsin residents please add 5.5% sales tax. ◆

But Life Options was not finished with the *USAT*. There were still theories to be tested, questions to be answered, research to be done…and the *USAT* figured prominently into a new phase of Life Options inquiry.

TEXAS-*USAT* STUDY

Many people in the renal community, and Life Options foremost among them, believed rehabilitation was a "good thing" that would help patients to live more fully. But without proof, rehab would not be widely incorporated into patient care plans. The relationship between rehabilitation activities and positive outcomes had to be demonstrated through research.

In 2000 the ESRD Network of Texas (Network 14) and the Council of Nephrology Social Workers (CNSW) of North Texas provided Life Options with a chance to do just that. The Network mailed the *USAT* to every Texas dialysis center. A total of 169 centers returned their surveys to the Network. Facilities that assessed patients' physical and mental health functioning (using the SF-36) provided this information as well. After removing identifiers, the Network forwarded the data to Life Options.

Results of the Texas-*USAT* study demonstrated that as many as 57% of facilities in Texas were doing rehab at some level, by the end of 2000. In 1994, when the *Exemplary Practices* competitions began, only a handful of U.S. dialysis facilities were believed to be carrying out rehab programming.

When *USAT* scores measuring rehab were compared with the facilities' average physical component summary (PCS) scores and mental component summary (MCS) scores, the findings were clear: centers that were doing the most rehab activities also had patients with the highest mental health scores.[2]

This is important, since mental health is a key component of the experience of overall health and is strongly related to quality of life. This fact alone supports the value of rehab.

But there is more: research demonstrates that higher mental health functioning is associated with lower morbidity and mortality.[3-7] The implication is that if we can improve patients' mental health functioning with rehabilitation—we are actually improving their chances for survival and wellness.

LIFE OPTIONS APPROACH

The unique research and response approach has served Life Options well in its endeavors to explore and understand rehabilitation and to make rehabilitation a reality in the lives of every kidney patient.

For people with kidney disease, successful "rehabilitation" means living long and living well. What the two-pronged research and response Life Options approach has helped us to understand and apply is the notion that rehab is the key to unlocking patients' "life options." ◆

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Since 1993, Life Options has been making important contributions to kidney patient education and research. You can help ensure that our work continues, by making a tax-deductible donation to The Medical Education Institute to support the Life Options Rehabilitation Program. Any amount is welcome. You can offer your tax-deductible financial support to Life Options in one of two ways:

- Donate on-line: Click the "Support the Life Options Rehabilitation Program" button (above) on the Life Options website (*www.lifeoptions.org*) to donate through a Verisign™ Secure Site run by *Network for Good*, a resource for non-profit organizations.
- Send a check: Print out a donation form at the Life Options site listed above, fill it out completely, and mail it to the address provided on the form. We will mail you a receipt for tax purposes. ◆

COMING IN THE NEXT ISSUE OF THE *RENAL REHABILITATION REPORT* (*RRR*)...

The topic of employment will be the focus of the September 2003 issue of the *RRR*. Featured articles will include:

- The benefits of employment for patients, providers, and payors
- Strategies and techniques to help patients get and keep jobs
- A personal success story of maintaining employment while on dialysis
- Tips for centers on how to work better with VR to improve employment

This issue coincides with the July release of the updated and expanded Life Options booklet, *Employment: A Kidney Patient's Guide to Working and Paying for Treatment*. The booklet—updated with support from the Forum of End Stage Renal Disease Networks and Amgen Inc.—will be available to download for free from the Life Options website (www.lifeoptions.org), as well as on ESRD Network websites.