Improving the Quality of Life of the Terminally Ill

Exploring How Citizens can Provide Companionship and Stimulating Activities to End of Life Patients through Community Exchanges/Time Banks

Tag Words: palliative care, hospice care, end-of-life, terminal illness, quality of life, Affordable Care Act, pediatric palliative care, Time banks, Community exchanges,

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Summary:

Patients entering hospice care is generally considered to be negative news amongst family and friends as it signifies the end of the life with healthcare services that primarily concentrate on alleviating their pain and suffering through medicinal means. Here we wish to advocate the transition to palliative care as the main component in end-of-life management and to concentrate on quality of life during this very sensitive time. Palliative care concentrates on improving patient care and life-quality throughout the illness from the time treatment begins until death. In order to aid in this initiative, we explore the idea of using community exchanges or TimeBanking, where community members provide meaningful face time with patients in hospice and palliative care programs, possibly through entertainment or educational programs, for little to no cost to the patients in these facilities.

Video Link:
https://www.youtube.com/watch?v=2e3NlZiSYgo&list=UUts4_1WyqXMmVDfu9ZffstA

Transitioning End-of-Life Treatment to Palliative Care (AM)

Rather than concentrating on only those who have already been terminally diagnosed, palliative care offers a broader frame of support to those facing a life-threatening illness. As most palliative care programs are provided through inpatient consultation services, a team of varying specialties work alongside the leading physicians in bridging the communication gap of negative information in relation to their prognosis. These services make their main emphasis of care on support by giving aid to patients and their families when navigating the complexities of the medical network. They assist in making various medical-related decisions as well as provide emotional and spiritual support outlets as needed. Palliative care, unlike hospice care, its counterpart, has the ability to be accessed at any point during the duration of the patient’s illness, giving the prospective clients a more descriptive and optimistic view of their care. As health insurance companies cover the majority of the expenses for this newly arisen treatment, the continuous integration of these programs prove that there are endless options to improve quality of life for extremely ill patients, whether that means that they are in a transitionary period or terminal.

The Underlying Issues of Hospice Care (AM)
With its foundation in the mid-20th century London, the term “hospice” has encompassed the societal norm of treating terminally ill patients. Hospice accounts for approximately 36% of deaths in America per year and is particularly recognized as a type of care where patients have “the right to die pain-free and with dignity, and that our loved ones will receive the necessary support to allow us to do so” as stated by the National Hospice and Palliative Care Organization (1). As the focus of this type of care is on the medicinal alleviation of pain, hospice care is provided in homes, hospitals, nursing homes, rehabilitation centers, and even independent hospice centers to no specific age, religion, race, or illness. Although this type of care has the most positive of intentions, the negative connotations of death associated with hospice care has created a complex issue in how to care for individuals suffering from chronic illnesses.

The first home hospice program in America was established in 1974 and since then, more than 4500 programs, accommodating over 1.3 million Americans, the majority of whom are suffering from chronic conditions, have been established (3). As hospice became more accepted as a health care treatment, the Medicare Hospice Benefit (MHB) was enacted in order to have hospice services be covered by the majority of insurance plans and other medical and health care agencies. Due to the fact that here in America most patients receive this hospice care from home, the MHB supplies them with the required medical staff and equipment needed to provide the appropriate relief. Included in the required equipment are the appropriate medications prescribed for end-of-life comfort (3). Although approximately 84% of hospice patients receive coverage by the MHB, only about 8% are reimbursed for various costs stemming from the restrictions that are placed on the various aspects of disease treatment. Specifically for those patients involved in home hospice care programs, admission into hospitals and the specific treatments associated with such are very poorly defined. Hidden in the fine lines of the MHB by Congress, American hospice coverage by the Centers of Medicare and Medicaid Services does not allow for treatments given with the intent to possibly cure them of the disease (2). As a result of this, many diagnostic tests that are prescribed by the doctor become the financial responsibility of the patient and the hospice care agency, rather than the insurance company. As many of these tests are not continuously beneficial and are usually very expensive, many hospice care agencies do not approve of them. This leaves the financial burden upon the families of the patients and due to this; many patients refuse such treatments, even if they could be a significant improvement upon their quality of life.

While as a result of the Medicare Hospice Benefit, hospice has become a widespread and accepted form of end of life care, it has more recently shown that hospice programs have been used inefficiently and are underutilized. An estimated 36% of terminally ill individuals in 2006 passed away in hospice programs with an average life expectancy of about 21 days (1). This is a result of hospice only being employed at the very late stages of illness and completely eliminating all forms of curative treatment once these programs get involved. If these programs were to begin assisting the patients earlier in treatment, it has been proven that families and patients would receive the maximum benefit of the many hospice expenses (1).

**The Recognition and Integration of Palliative Care (AM):**

With society’s alienation of hospice and end-of-life care as a separate entity of the health care system, there was an extreme lack of attention to not only the patients in this category but also to
their families. With the support of the American Board of Hospice and Palliative Medicine, the American Board of Medical Subspecialties recognized palliative care as a subspecialty of medical care in May of 1996. Even though these were new approaches to quality of life care for those facing unpredictable illnesses, many patients were unaware of how to obtain such care and where there was information about it, as raising public awareness was a very large issue. According to Sean Morrison, M.D., a palliative care expert at the Icahn School of Medicine at Mount Sinai, the medical field lacks as a whole to truly engage with the public, physicians, and politicians in correcting the negative stigma when associating palliative care with hospice care. As this is seen so frequently, Dr. Morrison believes patients are not referred to palliative care specialists until it is too late in their illness due to fear affiliated with this term (5). In recognition of these fears, the World Health Organization (WHO) on January 23rd, 2014, took the very historical position of publicly adopting the integration of palliative care treatments. With an estimation of 40 million people requiring palliative care annually, the WHO strongly urged society to see palliative care as a “continuum of care,” solidifying its role in healthcare systems on a global scale (4). With this push for palliative medicine integration, they also advocated for the enhanced training of health care workers in supplying patients with relevant medications in addition for the support of less developed nations in increasing technological abilities. Although palliative care programs had already been flourishing across the nation, the fear for continuous treatment began to subside, and these programs have taken an even more significant role in society.

In specifically defining palliative care, the World Health Organization came to create a concrete definition to officially differentiate both palliative care and its negative predecessor. As an approach to improve quality of life, palliative care assists patients in addition to their families facing the uncertainty of an illness (4). Through the relief of discomfort by means of early identification and evaluation of treatments, palliative care programs intend to enhance quality of life, and influence the course of a patient’s illness in a positive manner. Unlike hospice, palliative care integrates therapies, if it is early enough in their illness, which have the utmost intention to prolong life such as chemotherapy or radiation therapy (4). The most significant aspect of their explanation was their recognition of death as neither attempting to hasten or postpone such a possibility. In their focus on support through psychological and spiritual aspects of palliative care, these programs encourage survival, but more importantly, honor death as a normal process of life. With their team approach to care for the needs of these individuals and their loved ones, palliative care programs deem it extremely necessary to support them as a system, allowing patients to live as actively as possible, in addition to aiding the families in their own bereavement (6).

Children’s palliative care (SS):

Each year, approximately 500,000 children in the United States cope and 50,000 children die from life-threatening conditions. Children’s palliative care, although very similar to adult palliative care, require a more comprehensive, compassionate, and developmentally appropriate focus on their care (8). For children, palliative care is the active total care of the child’s body, mind and spirit and also involves giving support to the family. With this treatment starting after the diagnosis of their illness, it is continued whether or not the child is directly receiving treatment related to the disease. The goal for these programs is to alleviate the child’s physical,
psychological, and social distress, believing that effective care also includes the family even if resources are limited. In addition to these evident important focuses, they commonly make use of community resources, as they are mainly located in tertiary care facilities, community health centers, or in the child’s home (4).

Differing from the approach to adult palliative care, pediatric palliative care places a limited concentration on death and an increased concentration on family bonding. The specific targeted aims including curing and healing practice, allows for these approaches to become instrumental for improving the quality of life, maintaining a patient’s dignity, and ameliorating the suffering of seriously ill or dying children in ways that are appropriate to their upbringing, culture, and community. Pediatric palliative care is family centered, as it helps with coordination of care and communication between medical professionals and family members. With this type of integration, families are given more ability to choose the proper course of treatment that correlates with their values, traditions, and cultures. Like hospice care, palliative care realizes that people of all ages die and that this should not be ignored; however it focuses on improving quality of life and living while the opportunity presents itself (9).

Palliative care professionals can provide much-needed support by educating the family about what is to be expected as the child progresses through the trajectory of their illness. These professionals are willing to discuss the possibility of death, the potential for physical and emotional suffering and the strategies for its prevention and treatment. The four categories of symptoms that are most distressing to pediatric patients and their families are pain, gastrointestinal disturbances, dyspnea (trouble breathing), and neurological changes. Effective pain management seen in palliative care programs involves frequent assessments for best method of treatment, knowledge of various types of medication and therapies, as well as open communication. Several pain ratings exist for pediatric patients, the most common of which is the numeric scale, “rate your pain on a scale from 1-10.” Providers should discuss pain management goals with patients and families to determine a balance between pain management and sedation when using stronger pain killers. Gastrointestinal disturbances such as nausea, vomiting, diarrhea, decreased appetite, and constipation are not uncommon in children with advanced diseases (10). Whenever possible, it is important to treat the underlying cause of the disturbance, because persistence of these symptoms can cause serious irreversible damages and discomfort. Neurological disorders can be the most disturbing and unpredictable for family members. If it is possible to manage these symptoms, palliative care programs emphasize that doing so should not be questioned.

While pediatric palliative care may not seem much different from adult palliative care, it is important to take into account that these children, in most cases, have not had the chance to live a normal life. Offering them opportunities to have any form of a childhood is beneficial, which is why it is of utmost importance that one should begin palliative care as soon as a child has been diagnosed. Offering support for the family and managing severe symptoms of the child’s disease can allow for a myriad of opportunities that the child may not otherwise have had.

**Utilization of Insurance for Palliative Care Alternative (AM)**
As the cost of healthcare has begun to reach unaffordable heights, the ability for many to pay for health services has been a national effort for quite some time. Even with the establishment of the Affordable Care Act (ACA) in 2010, the ever increasing health insurance premiums make affording hospice care much more difficult. Having an increasing impact on hospital and healthcare spending, palliative care teams are continuously providing a highly structured, organized system for delivering care. With the 138% increase in palliative care programs in hospitals since 2000, there has been a remarkable reduction in pharmaceutical costs, even more specifically in hospital costs through a decline in hospital stays, ICU stays, and unnecessary tests (2). With the large majority of patients utilizing palliative care pursuing curative therapies, the Medicare Hospice Benefit was enacted to not cover such remedies. As stated above, hospice care is considered to be an all-inclusive treatment, and the coverage for these programs can vary due to their neglect for curative treatments. With the possibility of poor coverage of needed services, researchers and palliative programs alike have found that the substantial increase in palliative care programs across the country can be attributed to the much more affordable insurance coverage for the needed services.

As the seriously ill account for over half of America’s total healthcare costs, this special facet of medical care utilizes the many services that are similarly covered by the large majority of health insurance companies. Much like a referral to a cardiologist or a neurologist, curative treatments through these inpatient or outpatient programs vary in coverage, as the majority of healthcare providers do not recognize the term “palliative care” (26). With separate billing similar to that of a doctor’s visit, inpatient and outpatient care often does cover many of the medical service’s needs, such as prescriptions, chemotherapy, and medical equipment (14). With President Barack Obama’s signing of the Affordable Care Act, the provisions that were congruent to access to quality palliative care were removed (except only for children who are able to receive hospice care and curative treatments at the same time) from the health care reform bills due to the negative perceptions of the care provided (12). Although it is not recognized in such a formal matter, several resources related to the payment and quality of reform that impact palliative impacts are still evident. This law offers opportunities to these programs with which they can be a part of the progression and implementation of new payment options and delivery systems such as patient-centered medical homes, accountable care organizations, and the bundling of payments (13). Not only hoping to control the costs of health care for this excessively needy category of patients, but these models also hope to improve the quality of care for these individuals. Since its establishment, the ACA has planned for a $464 billion spending reduction over a ten year period through Medicare, reducing the annual payment updates to hospitals and other healthcare providers (12). With palliative care programs making their way into cancer centers, emergency departments, and outpatient settings, the increasing simplicity of utilizing palliative care has met the criteria for numerous interested subjects with varying medical coverage.

Cultural differences in medicinal approaches (SS)

While the opinion of medical professionals should be greatly valued when it comes to decisions made for terminally ill patients, the cultural background and beliefs of individuals are equally as important. One’s culture greatly influences peoples’ view on illness, suffering, and death, and therefore influences their use of medical resources. Attitudes towards advanced directives,
which are written statements of a person’s wishes regarding medical treatment (16), and end-of-life care often vary depending on a person’s beliefs. In more recent years, however, it has become increasingly difficult for family physicians to judge the proper course of treatment for individuals of different societal backgrounds. Although cultural proficiency guidelines exist, there are not many resources showing physicians how to apply these guidelines to actual patient care. Enhanced cultural competency, an identified need for health care providers for those especially those dealing with the terminally ill, has been erected in the face of such an issue. With this increased need, it explains that a physician must have a clear understanding and recognition of the unique influences culture has on a patient’s attitudes, preferences, and decisions around end-of-life care. Not only does this greatly affect the possible outcome of the illness, but it improves the communication that is vital between a physician and the prospective patient.

With the possible influence of various medical professionals, Americans gives autonomy a significant amount of importance when it comes to the mediation of their care. This view however, may conflict with that of other ethnicities and, as a result, cause fragmented care, inappropriate symptom management, miscommunication with the patient and family, and sometimes a difficult death for the patient (9). Palliative care professionals note that it is important to remember that preferences not only vary between different cultures, but also among individuals within each culture. These programs make it evident in their care policies that a patient’s association to a specific group should not allow one to assume their personal preferences. Due to these sensitivities, communication is of utmost importance in providing the best individualized care for each patient (16).

In many cultures, death is a very sensitive subject, as many do not consider it acceptable to openly discuss it. Death in many cultures is associated with bad luck, causing loss of hope for a positive outcome. For those who have these beliefs, the family members may request that the patient not be told the prognosis of their illness, as collective decision making as a norm. In these situations where the family holds all responsibility for health care decisions of the patient, they therefore expect to be told information first (16). Pain management also varies among different cultures, as some see certain treatments as a sign of weakness (i.e request pain relief), differing from other cultures who may have an indirect communication style and therefore do not request pain relief until it is offered. If the physician is unaware of the patient’s beliefs, the patient may be going through extended suffering that could otherwise be avoided (9).

In order to make sure that the best possible care is provided to patients, a cultural assessment must be performed. This provides a systematic way of gathering and documenting information about patients cultural beliefs, meanings, values, patterns, and expressions as they relate to a patient’s response and perceptions on an illness. This can be performed by any healthcare provider with modifications to the types of questions asked based on the provider’s specific disciplines. It is important that this assessment be integrated into the patient's treatment plan in order to ensure the best care possible as well as continuity of care. There are a number of assessment tools that may be used to carry this out:

- Kagawa-Singer & Blackhall’s ABCD Cultural Assessment Model
- Giger-Davidhizar’s and Huff’s Cultural Assessment Models
- Kleinman and Campbell’s Patient Explanatory Assessment Model
Integrated Model of Palliative Care (SS)

An implemented solution that has been found to continuously improve palliative care programs is the use of an integrated models. This has been supported by the American Academy of Pediatrics and includes the offering of palliative care at diagnosis and continues as the person’s illness progresses, neglecting a specific outcome. When proximity of death is used to determine if a patient is applicable to a palliative care program, many patients die without ever receiving the benefits of such individualized, family-centered care. It is important to integrate such treatments as early in the disease prognosis as possible to ensure that each person, no matter the age, receives the best care possible. Curative treatments, or life-prolonging treatments, are designed to reverse the progression of a specific disease, while many palliative treatments focus on relieving the symptoms that accompany these diseases, regardless of their impact on disease progression. When these two ideas are seen as conflicting, it hinders the appropriate provision of palliative care to any patient living with terminal conditions (18).

As physicians and researchers continue to discover new and emerging treatment opportunities, many medical professionals have found it difficult to define such therapies as either curative or palliative (19). An example of which is seen in mechanical ventilation. Often viewed as a life-prolonging therapy, it is believed that this should not be used once the family has decided to turn to palliative care. Such support however, especially noninvasive forms of positive pressure ventilation, may relieve the symptoms from dyspnea, difficult or labored breathing, and significantly improve a child’s quality of life (19). Therefore, if one were to separate the two concepts, patients may be deprived of comforting treatments just because they are in the “wrong” stage of treatment.

Community involvement in the care of the elderly and infirm:

Fureai Kippu, “caring relationship tickets”, is a program that has been successfully operating in Japan since 1995. This program is an electronic banking system that was originally designed to provide health care for the elderly. With such a system, individuals can earn credits by caring for a local elderly or sick person and each hour of service can be banked electronically. These hours may then be accumulated to allow them to utilize similar services, or may be transferred to a person of their choice who needs similar help. After the extensive use of these programs, it has been found that people tend to prefer the services offered by those paid with Fureai Kippu over those paid in Yen (monetary unit of Japan), due to this system’s basis on genuine care and compassion (20). Found not only in Japan, community exchanges, also known as “Time Banks”, are used in various communities around the world, sharing similar concepts. People participating in each time bank are able to provide services for hours over monetary gain, using the hours they have earned for other services offered by other members of their particular community exchange/time bank (22). Time Banks are a way that everyone can give back to their community, enabling members to share their talents within their own community in addition to gaining both financial and social capital. Receiving something tangible in return for those in
these community exchange groups has become an added incentive, as some individuals waver in their legitimacy (21).

As Time Banks continue to spread across the country, there have been many that have shown greater success than others due to popularity in certain counties across America. These systems have been seen to be created with much flexibility, as members get involved with their specific abilities at their available times. Examples of successful time banking programs in the United States include the Visiting Nurse Service of New York’s (VNSNY) and the Community Connections Time Bank in Lehigh Valley, PA (24). VNSNY is the largest non-profit home care agency in the America, launching their first time bank in December of 2006. With member count of over 1700 people, ages 6-97, they have found themselves exchanging a wide-variety of services such as cooking, language translation, escort to the doctor, minor home repairs, etc (23). These exchanges occurred between a variety of age groups, income ranges, and ethnic backgrounds and many local businesses have been seen to provide discounts to Time Bank members (25).

**Community Action: Introducing Time Banking to Palliative and Hospice Care Facilities**

For our community action project, we hope to have palliative and hospice care facilities involved in these Time Banking systems. If people were to offer their services to the patients in these various care programs, participating in the time bank would allow the assorted end-of-life care organizations to provide better quality living conditions without worrying about the cost. In child care facilities, the members of the time bank can provide educational and tutoring activities to allow the children, who have not been able to go to school due to their illnesses, to receive some form of education. In the adult facilities, people would be able to provide stimulating activities, such as music lessons or diverse forms of entertainment, to improve one’s quality of life through the course of daily treatment. There is no particular age range for participation in this program because these programs can accommodate the service abilities of all types of people, religious organizations, and various community service groups. It is the goal of our initiative to have these time banks not only be integrated in hospice centers in hospitals, but also possibly for in-home treated patients. Rather than just community activities at these specific centers, patients receiving treatment at home would have access to the time bank and can request personal services as well, such as driving them to doctor’s appointments or assisting with daily tasks.

We provided information about Time Banking to several hospice and palliative care programs in New Jersey (see list below). We signed up the hospice and palliative care programs that were interested as members to the appropriate “County State Strong Time Bank”. By involving hospice and palliative care facilities in programs such as these, we can develop a more caring and stronger community, in turn, improving the quality of life for individuals suffering from serious illnesses.

**Hospice and Palliative Care Facilities:**

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<thead>
<tr>
<th>Name</th>
<th>Email</th>
<th>Phone</th>
<th>Website</th>
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(21) Data from various sources.
(22) Data from various sources.
(23) Data from various sources.
(24) Data from various sources.
(25) Data from various sources.
| Trinitas Region al Medical Center | vramsberger@trinitas.org | 908 - 994 - 585 1 | http://www.trinitashospital.org/palliative_care.htm | Union |
| Liberty Health - Jersey City Center | npain@libertyhcs.org | (201) 915 - 205 8 | http://www.barnabashealth.org/Jersey-City-Medical-Center/Our-Services/Geriatrics-Palliative-Care.aspx | Hudson |
| Monmouth Medical Center | jisrael@sbhcs.com
Didn’t work! Call and ask for email! | (732) 923 - 796 2 | http://www.barnabashealth.org/ | Monmouth |
| Morristown Memorial Hospital | karen.knops@atlantichealth.org | (973) 971 - 513 6 | http://www.atlantichealth.org/morristown/our+services/hospice/ http://www.atlantichealth.org/morristown/our+services/palliative+care/ | Morris |
| Jersey Shore University Medical Center | sutton@meridianhealth.com | (732) 776 - 454 6 | http://www.jerseyshoreuniversitymedicalcenter.com/JSUMC/ | Monmouth |
| Robert Wood Johnson University Hospital | mary.kelly@rwjuh.edu | (732) 828 - 300 0 | http://www.rwjuh.edu/rwjuh/palliative-care-program.aspx http://www.rwjuh.edu/rwjuh/Hospice.aspx | Middlesex Somerset |

An email was sent to each program coordinator in order to share the importance of these programs:
Program/Professional,

Hello, my name is Susanna Simkin and I am a senior in the School of Environmental and Biological Sciences at Rutgers University. My partner, Allison McKenna, and I are working on a project to improve the quality of life of chronically and terminally ill patients.

I would like to introduce you to a new program that would enable your organization to enlist volunteers that could provide enriching programs for your clientele. The new “County State Strong Community Exchange” is a network that engages community residents to help one another. A resident could spend an hour/week providing, for example, knitting lessons to a patient and in return, that resident could then receive needed services such as home repair from other community residents.

While medical professionals are vital in controlling symptoms and managing pain, many patients do not have a strong emotional support system or the financial means for additional aid. Our Community Exchange program is a way for those in need to see out stimulating and fun activities to improve their well-being without economic boundaries.

You can visit the website (countystatestrong.org) to get an idea of how it functions. Your organization could sign up as a member and help coordinate services for your clientele (at no cost to you). Please see the attached membership application. You may choose to mail it in to:

Dr. Julie M. Fagan, Associate Professor, School of Environmental and Biological Sciences,
Rutgers University, 84 Lipman Dr., New Brunswick, NJ 08903

or provide the information requested in an email to countystatestrong@gmail.com after signing up as a member on the website.

I have also attached a PDF explaining the significance of a Community Exchange and how it can benefit the patients in these care programs.

I understand that you may have questions regarding involving the public with patient care prior to signing up. Please feel free to ask me or my partner Allison, or direct your questions to the County State Strong Community Exchange Coordinator, Dr. Julie M. Fagan, Ph.D at countystatestrong@gmail.com.

Susanna Simkin and Allison McKenna
School of Environmental and Biological Sciences
Rutgers, The State University of New Jersey

A follow-up phone call was made in order to reemphasize the significance of these Time Bank programs and to answer any questions that the coordinators may have had regarding the program. After each establishment was contacted for such a response, a voicemail was left for each of the above hospice and palliative care facilities:
Hello, my name is Allison McKenna, and I am a Rutgers, The State University of New Jersey, student calling along side of fellow student Susanna Simkin in regards to an email you have hopefully received. Under the guidance of Dr. Julie Fagan (Ph.D), an email was sent to you regarding the possibility of integrating your facility into the appropriate Community Exchange program for your county. The details of the email explain what I mean by a Community Exchange Program and how you can hopefully get involved. If you have any pending questions or concerns, please contact us using the information listed for you at the end of the email. If you have not received such an email, please contact Dr. Julie Fagan at (610) 847-2411, and we will make sure the information regarding our initiative is sent to the correct address. Thank you, and have a great rest of the day!

Despite our attempts to involve these palliative care programs in the Community Exchange program, our efforts were to no avail. Out of all the places we contacted, only Robert Wood Johnson University Hospitals displayed any form of interest in the program, but when the a voicemail was left on their machine to follow up and possibly sign them up for the program, no response was received. Thus, unfortunately, there was not much interest in the programs we were offering. We believe this may be due to the fact that community exchanges are not yet commonplace and not in the limelight or effectively used and managed. In order for the community exchanges to work in such settings, there needs to be “buy in”/support from the agencies and significant effort to making them work. Once the potential benefits are realized however, we believe that a working community exchange would be viewed as well worth the time and effort.

References

Letters to the Editor:

Sent to: The Record and the Fair Lawn Community News
Dear Editor,

Fureai Kippu, “caring relationship tickets”, is a program that has been successfully operating in Japan since 1995. This program is an electronic banking system that was originally designed to provide health care for the elderly. Individuals can earn credits by caring for a local elderly or sick person and each hour of service can be banked electronically. These hours may then be used by that person in the future, or may be transferred to a person of their choice who needs similar help. People tend to prefer the services offered by those paid with Fureai Kippu over those paid in Yen, because this system is based on genuine care and compassion.

Community exchanges or Time Banks in use in various communities around the world share some of the concepts of the Fureai Kippu. People participating in each time bank are able to provide services for hours rather than money but they use the hours they have earned for other services offered within the time bank. Time Banks are a way that everyone can give back to their community. Time Banks enable members to share their talents within their own community allowing them to gain both financial and social capital. This capital may be banked on the Time Banks website and collected for future use. Getting something tangible in return (in addition to the satisfaction knowing that they’ve helped someone) is an added incentive for those individuals that express interest in helping others but fail to do so for a variety of reasons. Each county in NJ has its own Time Bank. Many of these Time Banks are young and are still collecting members. The county Time Banks throughout NJ are listed under “[County Name] NJ Strong,” and you may visit the Time Banks’ website for instructions on how to become part of this tight knit community.

As palliative care is aimed at relieving suffering and improving quality of life, it is important to consider how Time Banking can become a part of this process. Palliative care programs are designed for support and pain management of patients with very serious or terminal diseases. The palliative care team consists of the lead physician, who manages treatment plans, and several nurses and medical professionals who tend to the daily care of patients in these conditions. However, is this enough? When patients go home, they don’t always have the support they need to deal with such diseases. Involving palliative care programs in Time Banks can give patients the assistance they need from their community in addition to the professionals who tend to their medical needs. Members within the Time Bank can provide daily services such as cooking, cleaning, and driving patients to doctor’s appointments or treatment. While these may seem like very small favors in the scheme of such a serious illness, they will allow patients to focus on recovery and treatment instead of concentrating on minor daily tasks.

Sincerely,

Susanna Simkin
Rutgers, The State University of New Jersey
Improving the Quality of Life of the Terminally Ill

To the Editor:

In today’s society, we are sadly confronted with many family and friends who are not only chronically ill, but know those who have a terminal illness. When confronted with such a situation, hospice care is usually brought in as a care service for the patient, but the first thought that comes to mind is “death,” and fear is instilled not only in the individual but their families. Becoming its own sect of quality-of-life care for patients such as these, known as palliative care, is coming to light bringing not only curative treatment into play, but guiding families through such a difficult and trying time. When patients find themselves either in the hospital, care facility, or being sent back home, many require help not only with their medical needs, but other issues that may arise. After first being implemented in Japan in the late 1990’s, community exchanges, or better known as Time Banks, have been established around the world to allow volunteers to provide a variety of services. Rather banking actual money, these programs allow the participants to bank hours that they could later use themselves. As an excellent way for everyone of any age to give back to the community, Time Bank members are able to showcase their talents to others for good. With each county having their own Time Bank in New Jersey, many of them are still very young and continuously collecting members. Since many patients in palliative care programs are not found in hospitals, members of these Time Banks can provide many different services such as cleaning, tending to medical needs, transportation, and even cooking.

Not only are these Time Banks providing benefits to their members through service, but also they are more importantly helping those who have difficulty helping themselves. For more information, everyone can go to http://northwestnewjersey.timebanks.org to get themselves and their families involved with their communities in such a positive way!

Sincerely,
Allison McKenna
Rutgers, The State University of New Jersey
The School of Environmental and Biological Sciences