DRAFT

Building Community Competence

The Role of Gatekeepers in Preventing Late Life Tragedies

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To reduce the high and stable rate of suicide among persons over 65 both in the United States and Australia will require innovative and effective prevention and intervention strategies. This article describes one approach to a community-based suicide prevention program for home-dwelling and impaired at-risk elders. By training public and private citizens in surveillance, detection and referral skills, isolated and at-risk elders were identified for home visits by professional service providers. These trained "gatekeepers" become a life-saving link in the delivery of essential medical, psychiatric and social support services that, when effective, can enable elders to remain in their homes and to solve the problems in living too often resolved through acts of self-destruction. Since its inception in 1978, the Elderly Services program of Spokane Mental Health led to a sustained decline in suicide rates among persons over 65 in the county. The Gatekeepers program has now evolved into the QPR Suicide Risk Reduction Program for Communities, also briefly described here.

Background

In America and other countries, the majority of persons over age 60 live in our communities in their own homes or apartments. While suicide rates vary by gender and age, in the US suicide rates are highest among older white males (AAS, 2003). The data are in and their interpretation is clear: most elder suicides occur in our communities, not in institutional settings. More, due to stigma and other access problems, most elder suicides are not receiving competent medical and psychiatric care at the time of death (U.S. Department of Health, 1999). Thus, suicide prevention efforts that focus primarily on enhancing the quality of care, improving medications, upgrading the competency of healthcare providers to better serve elders can be expected to have no discernable effect on the elder suicide rate, *so long as those elders who would most benefit from such services never receive them.* Only by blending a public health outreach approach (surveillance, detection, and timely intervention) with in-home multidisciplinary team treatment and social support services, can those elders most at risk be identified and served to avoid premature institutionalization, disability and death.

In 1978, Spokane County (USA) residents aged 60 years and over were experiencing high rates of medical and psychiatric hospitalizations, as well as premature nursing home placements. Not a few were found dead in their homes from freezing (because their electricity had been shut off by power companies), or malnourished and expired (from lack of food and/or medications), or immobilized and nears-death by an injurious fall which made reaching a phone impossible. The dead were worrisome to health officials and the coroner, but few others. However, those found and in need of institutional care created a crisis, as much financial as humanitarian. Something had to be done.

Community surveys of the problem were conducted by the leadership of Spokane Mental Health, a publicly funded mental health center. A community-based multidisciplinary team of professionals, including social workers, nurses, psychiatrists and other healthcare professionals formulated a theory and designed a series of innovative steps to help resolve the growing crisis. It was the belief of the innovators that a unified community response was required, and that a partnership with public and private entities would be required. It was determined that at the community level both lay citizens and professionals must work together to achieve two common goals:

- A greater sense of shared responsibility for the care and welfare of community-dwelling at risk elders
- An enhancement in community competence in the identification and referral of those at risk before they required institutional care or died in their homes or apartments

The basic idea was simple: since those elders at risk of premature placement in nursing homes, hospitals or death did not come to us, we would need to go them. But to go to them, we needed to know who they were and where they lived. We needed case finders, people who had frequent contact with elders and who could serve as our "eyes and ears" in the community. We needed the willing assistance of ordinary citizens who could help us locate persons who might need our help.

Philosophy and Theoretical Assumptions

Fundamentally, our position was that all communities care about human life and will go to great lengths to prevent and mitigate human suffering. We defined community as *our community* – basically, Spokane County, or that geographical region our agency had agreed by contract to serve. Thus, while the majority of funding came from the State of Washington Division of Mental Health, other funds came from the federal government under the Older Americans Act, and still other funds came from county and city coffers, as well as through private companies, family donations and other sources. By simultaneously building shared community responsibility and individual and group competence to detect, identify, assess, manage and treat at risk elders, we encouraged our community to define itself as a caring, confident and competent community which shared the goal of preventing late life tragedies among our oldest citizens.

From our analysis of the social, medical, psychiatric, financial, transport, access and other challenges faced by elders in our community, a number of critical theoretical positions emerged, one of which was that our compartmentalized, poorly coordinated, traditional service delivery system was a failure. Since most late life tragedies occurred "outside the system" the system was not delivering on its promises. Rather than blame the victims for not accessing the service system, we blamed the service system for not accessing those most in need. The following assumptions emerged:

Those elders most at risk:
- tend not to self-refer for help
- tend to be treatment resistant
- frequently abuse drugs and/or alcohol
- dissimulate their level of despair
- minimize the severity of their problems

- go undetected by the system
- go untreated

We asked ourselves why those who most needed us did call or ask for help. We theorized the following sources of resistance to help-seeking

- Pervasive feelings of shame (I can't take care of myself)
- Suspicion of do-gooders (who put you in nursing homes)
- Fear of hospitalization and loss of personal control of one's life.
- Failing memory or failing mobility
- Fear of becoming a burden on others
- Onset of clinical depression
 - Onset of symptoms of dementia, from whatever etiology
 - Lack of social others or family who could advocate for and access the system of care

Thus, our first challenge was to accept the reality that those who most needed our services would rarely, and perhaps never, ask for them – even though these services were broadly advertised in the local media. When we conducted surveys of existing program utilization by elders in our community (meals on wheels, elder social support programs, etc.) we found the majority of clients to be quite healthy, mobile, cognitively intact, not mentally ill and socially active – hardly the population of persons most in need of services.

In brief, we determined we needed a public health model to better detect older at risk citizens in our community. We also needed a mobile mental health team trained to work exclusively with elders in their homes. And we needed primary medical care physicians to deliver care in the home, as many of those we identified had outlived their doctors and had no physician of record. To address the lack of knowledgeable and skilled workers, we created staff education and training programs in geriatric psychology and psychiatry. To address the lack of physicians, we approached the University of Washington Family Medicine Residency, Spokane, and invited them to assist us in conducting home-delivered medical diagnostic and outpatient treatment services.

To help us find those most in need would require the eyes and ears of community-based people who a) had frequent contact with elders as a routine part of their work and b) would be willing to be trained to recognize the signs and symptoms that may indicate an elderly person is in need of assistance. By appealing to employers of such persons, and to their sense of community pride and their basic humanitarian nature, recruitment to gatekeeper training was not difficult.

As we approached those organizations whose employees had frequent contact with elders and who might serve as gatekeepers, it was important to specify the nature and extent of the training program and the actions expected of those trained. We set clear limits for gatekeeper duties and responsibilities. For example, the training program would take no more than 90 minutes. There was no charge. Training was made available at the employer's convenience, not ours. If a night training class was needed, we did it. Training classes would be repeated at any time on request. Once gatekeepers were trained in the recognition of problems, their only other duty would be to call us (Elderly Services). Our agency assumed all medical-legal liability for the services

rendered and, most importantly, every referral made resulted in feedback to the gatekeeper. We recognized "good works" and rewarded not just the employees, but their employers. We sent thank you letters to the company CEOs, issued press releases noting their community leadership, and our directors and board members sent personal letters of gratitude.

The Training Program:
Our first step was to outline the expectations of effective gatekeepers. These were to:
- be aware and alert
- recognize warning signs and symptoms
- listen and observe
- know the referral protocol
- understand that gatekeepers are acting in the role of the Good Samaritan for the betterment of their home community

Next, we built a straightforward training program understandable to lay audiences. We taught participants that when dealing with an emotionally distraught or agitated older person, use a calm voice, provide gentle reassurance and support and to avoid arguments. We taught them to accept anger and fear and to keep their poise and balance.

We included a very short lesson in social ethics and that all of us have duty to assist those least able to care for themselves, including the frail, vulnerable elderly. We assured them that we did not force assistance on anyone, but that when a community understands its full range of alternatives and options, many problems can be solved before they become tragedies. We highlighted the goals of independence and quality of life, and that these are things all of us share as basic human values. We also outlined the rules of confidentiality, how we would respect anonymous referrals and what language we would use to maximize privacy while assuring relief for the older person in need.

In their roles as gatekeepers, we taught them what to look for, what to listen for and even to use their noses, e.g., to detect rotted food or a plugged toilet. In outline form, here are the categories of signs and symptoms we addressed to enhance their mental health literacy and knowledge (Raschko & Coleman, 1989):

- *Problems with personal appearance* - unkempt appearance, dirty or uncombed hair, unshaven, dirty clothes, inappropriate clothing for weather, body odors, etc.
- *Conditions of the home* - poor repair, old newspapers lying around, calendar on wrong month, little or no food, strong odors, many pets – animals appear neglected, garbage or litter, walks covered with snow, etc.
- *Mental status* - confusion, disorientation, inappropriate responses, forgetfulness, repetitiveness while talking, seeing, hearing, smelling, tasting, feeling things that are not there, false beliefs, suspiciousness, lack of trust, feelings one is being mistreated or harmed, fear of strangers and alcohol abuse
- *Emotional status* - complaints of not eating, problems in sleeping, evidence of alcohol use, e.g., bottles piling up, anger, irritability, hostility, appears sad or blue, talking of loss
- *Physical losses*? - complaints of hearing loss? Mobility losses? Now homebound when they were not before?

- *Personality changes?* - isolated, withdrawn, suspicions, angry? Is this different from earlier contact?
- *Economic problems?* - can't pay bills? Overpays or tries to?
- *The warning signs of suicide* - multiple losses? Suicidal communications, e.g., giving away personal possessions?

Having covered this problem recognition material in approximately one hour, we then taught them what, in many ways, they were most relieved to hear. As gatekeepers they did not have to solve the potential problems they had detected, they only had to do one thing: *call us!*

It is critical for any organization wishing to replicate this program that leadership clearly understand the commitment the agency is making, not only to the identified at-risk population, but to the citizen gatekeepers now trained to identify and refer what are, most frequently, reluctant referrals. Remember, the home-dwelling elders identified by gatekeepers are almost always in serious trouble and have already taken a "defensive position" regarding accepting help. Thus, resistance to offers of assistance are the rule, not the exception, and outreach staff must be trained in how to approach, re-approach and re-approach again people whose trust level with strangers is extremely low.

We believed that for a gatekeeper program to be successful, the gatekeepers must be considered "part of the team." To be effective, they must be supported, and they must have credibility with the agency and its clinical teams. Their judgment cannot be doubted or questioned about an observation or referral, lest they feel they have failed. While not every referral made was warranted, every gatekeeper was personally thanked for their effort. Every referral made by a gatekeeper resulted in a home visit to the identified elder.

Where assistance was needed, we sent various elements of an interdisciplinary team to the homes or apartments: clinical case managers, nurses, psychiatrists, physicians and, in later years, pharmacists. These professionals provided tactical evaluation, treatment, care planning and ongoing clinical case management, including coordinating everything from transportation, to small home repair to home served meals. To minimize obstacles for elders, roughly 95% of the services they required were provided *in the home*.

Results

The outcomes of this program have never been fully evaluated. As of this writing, the program has been operational for more than 25 years. Based upon an interim status survey conducted in 1992 (upon the occasion of the program winning the Innovations in American Government Award), the following outcomes were noted (EWAAA, 1992):

- In 1990, 745 new clients, or 42%, of all new referrals to Elderly Services were from trained gatekeepers, while the remainder came from traditional sources, including families, government agencies, doctors and hospitals. Thus, almost half of all referrals of at-risk elders are from non-blood relatives/citizens acting as Good Samaritans
- Eight out of ten of the most severely impaired elderly were identified by and reached through the gatekeeper program, not through traditional referral sources

- As a result of the above, these institution-bound elderly were able to extend their independent lives and stay in their homes an average of nearly 22 months, or almost two years.
- Since 1978 the population of people over 65 has grown steadily in Spokane County, but the supply of nursing home beds has remained constant since program installation
- Since the program began in 1978, Spokane County's geriatric suicide rate has dropped from 28 to 16 per 100,000, and is now the lowest in Washington State

In summary, it is important for the reader to understand that, in 1978, the goals of the original gatekeeper training program did not include preventing late life suicides, or an almost 50% reduction in elder suicide rates. Rather, our goals were much more plebian. We only wished to reduce unnecessary psychiatric and medical hospitalizations and to help resolve the growing nursing home bed shortage. That the suicide rate for persons over 65 in our county began to decline was, frankly, pleasant news that only later began to make sense to us as follows: if you solve the problems people kill themselves to solve, perhaps they don't have to kill themselves.

Recent Developments
As a principal in the development of the above-described gatekeeper program, the author and a number of colleagues, including public health staff from the Spokane County Health Department, further refined the basic concept that a trained citizenry might be trained to act as suicide prevention gatekeepers, not just for elders, but across the age range.

As members of the human family, and living in communities as we do, each of us is surrounded by others, some of whom care deeply about our personal welfare and whether or not we live or die. It has been suggested that each of us has roughly 12 other persons intimately associated with us by blood, marriage, work, hobby or through other social and economic ties. These are the people who, in the event of our death, would make every effort to attend our funeral. It is these people, when trained in how to respond, who are the most likely to save us from a remedial medical crisis with the Heimlich maneuver or CPR. Similarly, in the case of a suicide crisis, these same intimate others must be trained in how to recognize a suicide crisis and how to respond with a bold intervention.

By reason of pride, age, gender or culture many of us may not be able to ask for help when we are suicidal, even though we would accept that help if it is freely, and even persistently, offered. Thus, if those around us can be educated to detect our distress, and even our coded pleas for assistance, perhaps gatekeepers could save lives that are otherwise lost.

For this social, value-driven interpersonal surveillance model to work, one must assume that it is through our intimate, interpersonal knowledge of one another that suicidal communications, behaviors and warning signs can be recognized, interpreted and acted upon in a quick and effective fashion. Without this gatekeeper function, this social safety network of educated and vigilant others to observe, interpret and respond to our distress calls, individual suicide will be difficult to prevent. Just as the crisis intervention model for elders described above led to positive outcomes, perhaps a broader application of the theory and concepts could be applied across much larger communities.

Suicide warning signs, our windows of opportunity
Suicidal warning signs and pre-attempt communications range from weak and coded to strong and clear, and may be sent to some potential gatekeepers, but not to others. While much research, including cross-cultural research, is needed on this dimension of human interaction and communication, it appears we now know enough to train ourselves and others to act as gatekeepers for those at risk.

Just as in the gatekeeper program described earlier, the *existing- relationship* with the potentially suicidal person cannot be overemphasized. This existing-relationship concept lies at the heart of any community-based model and method of suicide prevention, and thus leads to certain education and training requirements, e.g., the training of ordinary citizens in how to detect, recognize and respond to a person they already know who has, for whatever reasons, now become suicidal.

As with isolated at risk elders, even isolated suicidal persons living alone in their communities are in contact with someone who knows them: a family member, a case manager, a pharmacist, someone at church, someone…. It is this *someone* who must be trained to respond in a helpful fashion when suicide warning signs are detected, otherwise no rescue effort will occur and no life saving interventions and treatment will be initiated. For example, if the "best listener" in your life is not your husband but your hairdresser - and she is the person to whom you may communicate a suicidal wish - then it is your hairdresser who must be trained, not your husband.

In a simple experiment, each of us can place our name in the middle of blank page of paper and draw a circle around it. Then we can draw a dozen circles around our position and fill in the names of our intimate others, the people with whom we have a lot of contract, and the people who care if we live or die. While we may not communicate a suicidal wish to all of them, the person most likely to recognize our distress and provide assistance is already known to us; it is this person who needs training.

Once suicidal persons are detected by family members, intimate others or community gatekeepers, they must be referred for assessment and possible care by *competent community-based professionals*. Unfortunately, many healthcare professionals don't know what they don't know about suicide risk assessment and management (Bongar & Harmatz 1991). For a community to be competent to assist its suicidal members identified by gatekeepers, community providers must be trained in state-of-the-art assessment, management and evidence-based and effective treatments for persons with suicidal behaviors. For agency-based providers, a complete risk reduction program should be operational in that provider's agency, and should include the use of comprehensive clinical risk reduction practices and treatments.

The QPR community-based approach to suicide prevention
Expanding on the original Gatekeepers Program of Spokane Mental Health, the QPR for Suicide Prevention Program was originally designed and implemented in 1995. To date, using a train-the-trainer model, more than 250,000 people in the US and foreign countries have been trained in this basic suicide prevention gatekeeper role. QPR stands for Question, Persuade and Refer, three steps any ordinary citizen can be trained to take when a suicidal communication or distress

call is recognized. Based upon the concepts and theory of the original gatekeeper program, the QPR approach to suicide prevention differs from other suicide prevention programs as follows:

- QPR recognizes that even socially isolated individuals usually have some sort of contact within their community (e.g., family, doctors, teachers, supervisors, someone….).
- QPR teaches diverse groups within each community how to recognize the "real crisis" of suicide and the symptoms that accompany it.
- QPR stresses action, and active follow-up with each intervention.
- QPR trained gatekeepers play a pre-existing role in the life of the person at-risk for suicide.
- QPR is integrated with advanced suicide risk triage and risk assessment training for 1st responders and professional healthcare providers, thus creating a community-based "culture of safety."
- QPR addresses high-risk people *within* their own environments and *does not require suicidal people to ask for help.*
- QPR offers the increased possibility of intervention early in the depressive and/or suicidal crisis.
- QPR encourages the gatekeeper to take the individual directly to a community resource or healthcare provider.

Awareness and education are the answers
To accomplish substantial change at all levels of a community, an innovation-diffusion educational program designed to alter individual and group behavior in the majority of lay and professional community members is recommended. The QPR Institute has designed, built and tested a variety of training programs that, when taken together, constitute a systems approach to reducing suicide risk in individuals and in identified at-risk populations living in their communities. We believe the solutions to reducing the frequency and negative impact of suicidal behaviors any community are to be found *in that community.* Likewise, only that same community can define, enhance and employ protective factors against suicide.

Experts agree suicide is a preventable form of death (U.S. Surgeon General, 2001), and that lives can be saved with the implementation of comprehensive, evidence-based suicide risk reduction strategies, including public awareness campaigns, and by improving education and training in the identification, referral and treatment of potentially suicidal people. In our view, it is important for communities to also address the *perception of prevalence* of non-fatal suicidal behaviors and the potential benefits that can be achieved if this much broader range of self-destructive behaviors is addressed through a community-based risk reduction program.

For example, in unpublished surveys conducted by the QPR Institute and Washington State University College of Nursing Education at four hospitals in Spokane County, Washington, found that the cost of non-fatal suicidal behaviors resulting in hospitalization averaged $16,500 per episode of inpatient stay for adults and $27,500 per episode of care for adolescents. As provided by the Washington State Hospital Commission, these costs figures were exclusive of consultative psychiatric services, additional psychiatric hospitalization costs, or community follow up. In one year (1995), and in only four of our six hospitals, approximately 500 persons were admitted to hospital for medical treatment of self-inflicted injuries. Total costs ran into the

millions. Thus, any cost-benefit analysis of a community-based suicide prevention and risk reduction effort should include an analysis of the consequences and impact of *all* potentially preventable self-destructive behaviors.

Another frequently overlooked cost to communities are those associated with domestic violence, homicide and suicide. Evidence from the U.S. Air Force study showed that exposure to a suicide prevention program also reduced other adverse outcomes, including a 51% reduction in homicide, 18% reduction in accidental death, and significant reductions in measures of family violence. Thus, reducing the risks associated with suicidal behaviors, a community may also reduce the risks and costs associated with other-directed violence.

One key to successful implementation of a community-based program is to ensure that all community leaders *fully understand the true cost of self-and-other-destructive behaviors in their community.* Without this awareness and understanding, attitudinal support for the required broad community changes necessary to reduce risk factors for suicide, and enhance protective factors, will be difficult.

Clearly, the prevalence of suicidal behaviors in our communities demands attention. This attention, however well intended, should always be guided by those principles known to be effective in the prevention of human behaviors associated with increased morbidity and mortality (Nation, et. al., 2003). While the prevention of suicide has reached few of its broad goals to date, encouraging data is emerging that suicide is, in fact, a highly preventable form of death (Knox, et. al. 2003).

Lastly, suicide prevention is too important a task to be left to government. It is critical that businesses, labor unions and professional membership organizations be at the suicide prevention table. Since most American suicides are by employed men in their middle years (AAS, 2002), it is essential that employers become stakeholders in community-based suicide prevention programming, including using the worksite as a suicide prevention awareness and training venue. As has been demonstrated in the Elderly Services Gatekeeper program, it is only through public-private partnerships that a sense of shared community responsibility for preventing suicide can be achieved.

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