Community ASAP recruits from public to help adults living with dementia

BY REBECCA IHILCHIK

oronto caregiver Ron Beleno knows what it's like to have a loved one with dementia go missing. "My dad had Alzheimer's for over 10 years. He used to be a wanderer – he'd go on walks, become confused and get lost," Beleno says. "As a caregiver, it's one of the scariest times. Worst-case scenarios always pop into your head. You know their life could be at risk."

Beleno's father wasn't the only one. Wandering is one of the many anticipated symptoms of dementia; it's commonly cited that three out of five people with dementia will wander from home. For families and caregivers, the disappearance of a loved one with dementia can be devastating.

Motivated by his own experience and those of other families he knows, Beleno set out to find a better solution. He teamed up with Dr. Lili Liu, a professor of occupational therapy at the University of Alberta, to create Community ASAP: an alert system that allows first responders to trigger localized notifications to community volunteers when an older adult goes missing.

"When you interview individuals after a person who goes missing is found, either injured or deceased, you find out many members of the community spotted the person but didn't report it because they didn't think the person was lost," Dr. Liu says. "It seemed first responders were not using the biggest resource at their fingertips, which is community citizens."



With support from the Centre for Aging + Brain Health Innovation (CABHI) – a solution accelerator focused on driving innovation in the aging and brain health sector, led by Baycrest Health Sciences – Community ASAP is on its way to changing how we search for missing seniors.

How it works: When a volunteer signs up for Community ASAP, that individual can select up to five neighbourhoods they usually frequent – for example, those near their home and work. If an older adult goes missing in one of the designated areas the volunteer selected, all volunteers who have signed up to monitor that neighbourhood will receive an immediate alert through email or an app notification with a description of the older adult.



Dr. Lili Liu

Community members are asked to keep an eye out and contact first responders if they come across the individual.

Alerts will be sent out by the designated community coordinator, which, depending on the area, could be the police or an organization such as the local Alzheimer's Society. In some jurisdictions police already have their own public alert strategies, says Dr. Liu, in which case they would simply integrate Community ASAP into their protocols.

The hope is that the service will ultimately lead to shorter searches for missing older adults, which will in turn save first responders time and money.

The alert system, once available to the public, will be free for volunteers. Users

Paramedicine

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at the end of the day and that's improving their overall healthcare and confidence in their ability to care for themselves at home in a very safe and appropriate manner."

In Alberta, the model for community paramedicine is working so well, it recently expanded to be a province-wide initiative under Alberta Health Services (AHS). Referred to as EMS Mobile Integrated Healthcare, the program launched in Calgary in 2013 and in Edmonton in 2014. By last year it was supported by 33 paramedics who handled approximately 12,000 patient events.

This year, as it rolls out to include Peace River, Grand Prairie, Camrose, Red Deer, Lethbridge and Medicine Hat, it is expanding to more than 100 paramedics with 25,000 patient events anticipated.

Intake for community paramedic referrals is handled by two coordination centres located in Calgary and Edmonton.

When the team first goes into an area, it partners with community healthcare and continuing care staff – primarily supportive living, long-term care and private home care facilities – as well as with primary care networks to identify patients who may be managing chronic illness or are experiencing symptoms that require triage.

"Our team focuses on what we consider providing acute, episodic illness

support," explained Ryan Kozicky, director, AHS's EMS Mobile Integrated Healthcare. "So, we do diagnostic treatments and assessments in the home, but not case management."

Activities performed by Alberta's community paramedics range from collecting blood work or performing ECGs, to applying sutures or administering blood transfusions. Uniforms are business casual and the paramedics drive SUVs, working seven days a week from 6 a.m. to 10 p.m. in most regions.

Paramedics are using tablets, as well as Bluetooth-enabled devices, but coordination of information is expected to

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improve when the province's Epic electronic health record implementation goes live within the next few years. Preliminary cost analysis indicates that the treatments provided by paramedics in the home are \$1,100 less expensive on average compared to providing the same treatments in a hospital's emergency room, said Kozicky.

"The paramedic scope of practice really meets the needs of what we're doing in terms of providing those skills-based treatments," he said, adding that "the EMS infrastructure itself in terms of being able to provide mobile medicine, is something that's quite unique and paramedics can leverage."

Quebec-based Prehos Inc. is taking the same approach, leveraging its threeyear investment in developing EMS operational software to develop an EHR tailored to community paramedicine. Originally developed for Renfrew Country in Ottawa, the software is being used by five services in Ontario, including Parry Sound and Lanark County.

The app runs on an Apple iPad and is centrally managed by Prehos. "If a tablet gets stolen, we can erase it. If we have updates, we can push them over the air," said Prehos CEO and cofounder Christian Chalifour. "There's no IT involved at the user end and on our side, it's quite simple."

In addition to providing portable access to patient health records, the software is integrated with dispatch and scheduling so that an employee at the paramedic base knows what's happening in the field in real time, explained Chalifour.

Each patient record has a progress note that covers past visits and past reports, as well as information on medications, allergies and medical contacts. Paramedics can also take photos and add media files to their notes when visiting patients.

Chalifour heard about one incident when a paramedic observed a strange rash on a patient's leg, took a picture and sent it to the primary caregiver, receiving a response before the visit was complete. will be able to customize their experience by selecting the exact radius of areas they're willing to receive alerts for. By honing in on such a localized level, the app founders hope to prevent "alert fatigue" – the desensitization to a constant barrage of alerts.

Community groups, police, businesses, caregivers, and individuals living with dementia alike are eager to get involved, Beleno says. And, with support from CABHI, the Community ASAP team has been able to mobilize the grassroots-level interest quickly.

The CABHI connection: The Community ASAP team successfully applied to CABHI's Spark Program, receiving \$50,000 to test and validate their early stage innovation.

"I was just thrilled to hear that CABHI involvement comes with a whole fleet of acceleration services like guidance and consultation related to commercialization, licencing, and intellectual property," Dr. Liu says. "Those are services on top of the financial support which, I think, is brilliant."

The Community ASAP team is now in the process of testing early versions of the software in simulations with groups of volunteers, caregivers, and police in Calgary, Toronto, and Coquitlam, BC. They'll be using the feedback from participants in these trials to tweak the system.

The plan is for Community ASAP to recruit thousands of subscribers across Canada. In this way, the program will act as an awareness campaign in its own right: a call to action that will educate those who wouldn't necessarily know about dementia-related wandering.

Hope for those living with dementia and their families: The first target group, and the heart of the project, includes families of older adults with dementia and their communities. By harnessing the power of communities, the Community ASAP model has the potential to save the lives of older adults living with dementia – and give caregivers more peace of mind.

Sam Noh, a caregiver from Coquitlam, is hopeful about the prospect of Community ASAP. His father Shin Noh, who lived with Alzheimer's, has been missing since September 2013. "There were confirmed sightings of my father on the day he went missing. Unfortunately, news of my father's disappearance spread slowly and we received confirmed sightings days after," Noh says. "I truly believe if an alerting system such as Community ASAP were in place, my father may have been found."

Roger Marple is an individual living with dementia from Medicine Hat, Alberta who recently joined the Community ASAP team as a lived experience advisor. He, too, sees tremendous potential in the system.

"I've wandered and gotten lost about four times in my life – I even got lost at my job. It's a dreadful feeling when you're in a situation like that," Marple says. "Community ASAP resonated with me personally. I see such a benefit from this program in our communities. It's different from other programs because it's so localized. It makes total sense."

To learn more about CABHI, visit www.cabhi.com.