Measuring the importance of getting out and about

A Sydney study is using a new ‘lifespace’ app to explore community mobility and challenges for people with dementia. The results will be used to develop interventions that improve community access and engagement. Jacki Liddle, David Ireland, Fleur Harrison, Louise Gustafsson, Sandy Brauer, Robyn Lamont, Theresa Scott, Nancy Pachana, Perminder Sachdev, Kristan Kang and Henry Brodaty report

Many people may relate to the feeling of being able to leave the house and be out and doing things is a sign that life is good. The great news is that we have the science to back up this feeling.

Researchers have studied ‘lifespace’ – the geographical area in which you live and conduct your activities – since the 1970s. This measure records how often people moved about in different areas of their homes, neighbourhoods and further afield. The research has shown that there are key relationships between lifespace, and a person’s well-being, physical health and cognitive functioning. While these relationships seem important, they are not yet fully understood.

Now, there are new ways of monitoring lifespace using smartphones and this is helping us to figure out the needs and experiences of people living with mild cognitive impairment (people having some changes to their memory and thinking, but normal functioning) and dementia.

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For people who already had a cognitive impairment, those with a smaller lifespace have a more rapid deterioration of their cognition in the future compared with those with larger lifespaces.

Although we don’t know precisely how lifespace and health and well-being interact, this area clearly needs further study. Something that has been hindering study is that lifespace has been measured either by staff observing a person’s movements in a facility or by the person recalling their activity over the past week or two. Neither of these options is ideal for monitoring the activity levels of people living in the community and particularly those who have difficulty recalling the details.

Smartphones may provide a solution for this. GPS (Global Positioning System)-based location tracking, which is present on all standard smartphones,
allows passive monitoring of the latitude and longitude of the phone. This means it can show where the phone is on a map. This has been used by engineers at CSIRO’s Australian eHealth Research Centre and our team of health researchers at the University of Queensland to develop a custom Lifespace app (Liddle et al 2014).

The app keeps a record of the phone’s location during a specified period and calculates lifespace outcomes like daily distance travelled, percentage of time spent at home and number of trips into the community. The user just needs to carry the phone with them. As GPS is not effective within buildings, small Bluetooth beacons can be placed within the home to enable monitoring of the phone’s position within the home.

Our team now has a study underway in several Sydney suburbs measuring the lifespace of people living with dementia or mild cognitive impairment (MCI). Users carry the phone for one week and participate in an interview about their community mobility experiences and needs. Family members also participate in an interview.

Preliminary results are giving insights into the daily lives of this group, their experiences of using the technology and ways in which their current and future community mobility needs could be met.

**Sydney study of lifespace**

Fifteen participants (nine men and six women) to date have provided lifespace data using the app. These participants are aged between 81 and 90 years of age, living either in the community with a friend or family member (eight participants), alone (five participants) or in a low-care facility (two participants).

Use of the phone app and the beacons in the home have enabled us to capture the lifespace in numbers and visually. We are able to measure distances travelled, patterns and locations of activity in a day and percentage of time spent at home.

From the data collected so far, participants spend between 65-99% of their week at home. Their lifespaces span between 0.08 and 1.93 sq km during the week. Most participants do not leave the home every day, with a range of 0-13 trips (episodes of going into the community) recorded over the one-week period. The furthest distance travelled in a day ranged from 26m for one participant to 12.5km for another.

An example image (translocated to a different city to protect anonymity) is below.

The study runs through to the end of 2016 and as it progresses, the measured lifespace is being compared to reported community mobility experiences and barriers, as well as participants’ descriptions of effective supports.

We will also be looking at how lifespace relates to health and well-being for people. In doing this, means of identifying people needing support for their lifespace, as well as ways of supporting and enhancing lifespace will be developed in the expectation that these clinical interventions can be made available through health and community services in future.

**Community mobility experiences and needs**

The participants in the study were also interviewed about their community mobility and needs. They described a range of things that supported and encouraged staying mobile including lifetime habits; pleasant, safe walking environments; friends and family going with them; transport options and having personally important things to do that
The ethics of passive monitoring

When designing the Lifespace study and associated technology (described in the main article), the ethics of passively monitoring people were carefully considered (Carter et al 2015).

As the information collection did not require participants to actively decide to send data each day (it streamed automatically after initial consent), we needed to develop a way for people to choose how they participated. To give participants a simple way to opt out of data collection at any time we designed beacons with clear on/off buttons, gave simple written instructions about what information was being collected and how to opt out.

Opting out involved turning off the phone or simply not taking it. We purposefully did not ask participants questions about missing data (as part of supporting their choice to opt out of any aspect of data collection without consequence).

We gave participants a map showing their Lifespace for the week (the community locations they had recorded) and they indicated whether this matched their memory of where they went in the community.

Only one participant clearly opted out of some final days of the study by packing up the beacons and phone. She expressed concern that the technology may have been responsible for a disruption to her electricity supply.

Some participants described short periods of time where they expected there would be no Lifespace data (for example, if a phone was left on a charger for a few hours).

We also gave participants a phone number for support and a summary of the data they had collected after the week.

Reference

required community travel.

Barriers and difficulties were also identified including giving up driving; difficulties with walking; getting lost and feeling worried; having no reason to go out or no one to go with and roads and footpaths that felt dangerous.

Lionel*

Lionel described some difficulties he encountered with community mobility and how involving friends enabled him to continue to visit the shopping centre: “But I can get lost. I can go down there to the damn store. I can get in there and then I wonder where the dickens to get out of the place, you know. And then I go down with some friends. They go round like a rabbit and they know exactly where to go, but I’m not quite like that and that’s memory you know.”

Vera*

Vera described how the design of her community affected her ability to walk to complete necessary activities: Vera: “If I had to go to the post office or go to pay the rent, I would start to walk with my stick, and then they had low walls around the flat and I had to sit.” Interviewer: “Okay. You’d use them as a resting point? Very, very sensible.” Vera: “So walk some more, and then sit by the wall and rest, and that’s how I used to get around.” Interviewer: “Oh, okay.” Vera: “But I couldn’t do that here, because it’s …”. Interviewer: “There’s not enough low walls?”

Our research team is currently mapping these barriers and enablers from different clinical perspectives (occupational therapy, physiotherapy, psychology) onto existing clinical models and evidence-based treatments to enable development of clinical approaches to support maintenance of Lifespace and continued community participation. Understanding the barriers present within our communities can also help inform the development of universally accessible or dementia-friendly communities.

Future directions

Following this research, the Lifespace app could be used more widely to identify people who need support for their community access and engagement. The CSIRO’s Australian e-Health Research Centre team involved in this study is currently exploring ways to make the app available to other researchers.

Clinical interventions and supports to address barriers and encourage maintained Lifespace will also be developed, tested and translated into practice by the Lifespace research team. Knowledge about barriers and desired lifestyles will help inform the development of accessible and friendly communities.

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* Pseudonyms used to protect the identity of participants.

Reference

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