

# Searching for Solutions: Tools to Help Care Givers of Elderly/Aging and Patients of Dementia

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Global population aging is a success story. The number of people aged 65 or over is projected to grow to nearly 1 billion by 2030 and 1.5 billion by 2050, with most increases in developing countries. While global organizations (UN, WHO, World Economic Forum, etc.) and nations are focused on macroscopic issues (economic impact to economy, health care systems, social services), there is an immediate problem faced by local communities and family members of the aging – the task of Care Giving.



Many caregivers of older adults express satisfaction with their labors of love. But they often face challenges, especially when caring for people with chronic diseases such as dementia, diabetes, or heart failure. The day-to-day tasks may seem endless: arranging doctor's appointments and transportation, moving the person safely around, ensuring proper nutrition, and much more. Difficult situations, such as hospitalization and making decisions about long-term care, also arise.

[NIH on Health and Aging](#)

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## 1. Introduction

With aging comes an increased dependence on care-givers even for the most basic activities of daily living. Of all the possibilities of aging, none is more devastating to both the patients and the care-givers than the Alzheimer's disease and Dementia related conditions. While the race for cure for Dementia and deeper understanding is on, there is a pressing need for tools and methods to help the patients and care givers cope with the 36 hour days.

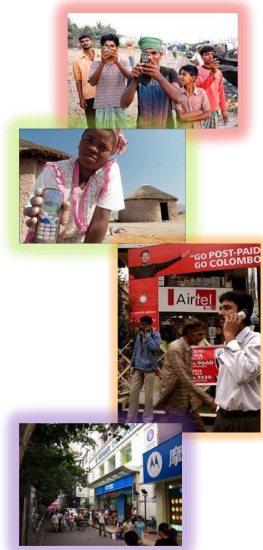
Although our journey started with a focus on dementia and MCI related conditions, we envision addressing the broader problem of elderly care-giving, specifically to help aging and elderly in general and their care-givers. The growing demand cannot simply be met by formal health-care system. More often than not, a large part of the care-giving responsibility will and still falls on the shoulders of informal care-givers (e.g., family members, friends, untrained/low-skilled care providers) and they will need help!

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We envision our user community to encompass care-givers (of all ages and education levels) and their care-receivers (aging, elderly, physically and cognitively challenged) from all economic classes around



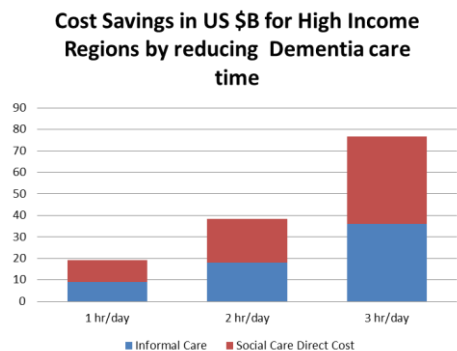
the world. This broad view greatly influences our design choices. Given the wide range of age and technical experience of our target user group, our tools and solutions need to be “smart” and usable by everyone. Our goal to reach all socio-economic groups means that our products need to be accessible and affordable. Given the computing power and almost universal ubiquity of mobile devices (smart phones, tablets), smart mobile devices are a natural choice as the ideal delivery vehicle for care-giving tools. In the environment our user community lives one size does not fit all; at the advanced age people respond to same problems and remedies in very different ways and the same person could respond differently at different times. Thus our products have to be adaptive and greatly personalized.



Creating infinite variations of products is not a viable option. Thus we need to build tools and platforms to enable our user community and volunteers to create their own solutions following the spirit of DIY and Makers.

## 2. Economic Impact of Care-Giving

Human cost of care-giving set aside, the economic impact on society is also significant. According to [World Alzheimer Report](#) 2010, in 2010 caring for Dementia was estimated to be a \$604B worldwide of



which more than \$500B was just in the Informal and Social care (non-medical care). This representing close to 1% of global GDP, there is a global concern on the financial consequences of this problem on the health of the nations. If cost is considered proportional to incidence of problem, then by 2050 the costs could be 4X the 2010 numbers. Although costs for non-dementia care would probably lower, it is worth noting that dementia only accounts for 10% of the 60 years and older age group. By some estimates the target user group (patients, elders, and care-givers) would be a 1B+ number worldwide.

Given the scale of the problem, even small improvements in

care-giving work-load has significant economic value to the society. For example, by our estimate, reducing care-giving workload by 1 hr. a day for dementia care has a value of about \$20B a year just in US.

### 3. Product Vision

#### What should we build?

Large part of care-giving involves supporting activities of daily living (cleansing, grooming, eating, etc.); additional activities such as shopping, banking, medication; discovering and coordinating care-givers and related resources; assuring safety through monitoring, etc. Understanding these needs and developing tools and methods (let us call them Tools of Necessity - **TON**) to address them has received a lot of attention from all sectors and is a very vibrant area for research, commercial products, and entrepreneurial ventures.



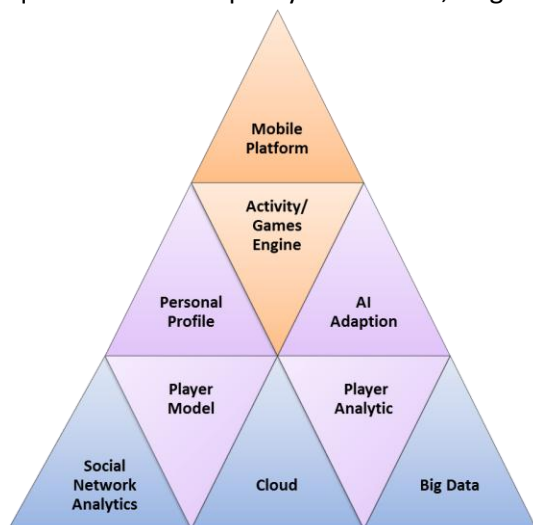
However, when asked, elderly overwhelming state they need most help with **Living Well** – a life of positive interactions, fulfillment, learning, and dignity (let us call these Living Enhancing Tools – **LETs**). At the same time care-givers



expressed need for help with **emotional/cognitive care-giving tasks, learning from the wisdom of other care-givers, and in coping with daily stress** (let us call these Burden Easing Tools – **BETs**). For example, care-giving checklists, engaging activities, tools to help communicate, memory aids, “what should I do” guides, context-based advice, etc.

#### Technologies

Creating tools to enable Living Well for elderly and care-giving tools (both for patient and self) for care-requires certain technical innovations. Smart phones and Tables are built to deliver highly refined and responsive user experience rivaling video-game machines. Care-giving has just the opposite requirements of simplicity in interface, forgiveness in touch events, acceptable resolution – closer to a



kids tablet than a game machine. The applications have to be personalized in their behavior (not just look and feel and user interface themes) to adapt to unique needs of the user and his/her changing cognitive abilities. The advice or options offered to care-givers has to be context sensitive. For example, Helen feeling anxious around 10 AM would call for a different response (may be a cup of coffee and a chair in Sun) than if she was feeling anxious at 3 AM in the morning. The applications themselves should monitor the performance or response of the user and learn patterns to be more effective. Often care-givers need to reach-out and seek advice from other care-givers. However, it will be useful if the advice can be filtered to those few that match the profile of the patient and the care-giver.

Essentially, our QET/BET applications should behave like a **coach and a care-giver**. And they encompass a large variety of exciting set of technologies: mobile computing, adaptive user interfaces, monitoring and learning, crowd-sourcing, analytics/data mining, integration with sensors (Internet of Things), and cloud-computing.

#### **4. Product Realization – Pitch and Pivot vs. Organic Evolution**

We have two groups of clients for tools and methods we hope to build: patients (aging, elderly, dementia, or MCI) and the care-givers. Our care-givers have two clients they hope to serve: the patients and the care-givers themselves.

##### **Pitch and Pivot – Discover the product**

The typical approach to building new products can be called a Pitch and Pivot method. This approach makes two implicit assumptions: (i) Most users of same class (patients or care-givers) will interact with our products the same way, and (ii) It is possible to define a common set of requirements and high value use cases to encompass majority of users. Thus the role of the innovator/entrepreneur is to discover the high value use cases and related. The innovator/entrepreneur puts forward a hypothesis about what the user community would find useful, develops some prototypes, test with users, learn and pivot.

An upfront challenge is to identify the initial product hypothesis: what tools the users would find useful. For the Care-giving problem domain, much expertise is available from neurology, psychology, nursing, social sciences to get us started with an initial set of product hypotheses. Assuming that there is a winning product hypothesis the developer hopes to find it through numerous pivots hopefully before the funding dries up.

Then there is another challenge: in the domain of Care-giving one size does not fit all; the assumption of a homogeneous user community and a winning product hypothesis does not hold. At an advanced age people are remarkably different. Even the same patient behaves quite differently under different circumstances. The product or solution space consists of a large number of variations; none may have enough critical mass to support a traditional business case. Pitch and Pivot will not scale since it is quite impossible for some group of researchers and entrepreneurs to really create infinite custom variations.

We need an alternative to Pitch and Pivot.

##### **User as Developer – Organic Evolution**

There are three factors that limit the scale-up of Pitch and Pivot: (i) Finite number of experts attempting to guess the next best winning product for patients and care-givers, (ii) A separate development process and team, and (iii) Need to recruit (and convince) user community for testing and spreading the word.

We propose to make users into innovators. Rather than a few trained professionals making tools for everyone, let users make their own tools! Their creations will not be slick, shiny, super hifi .. but they will serve the purpose. Users will solve their own problem in a manner that meets their needs. They will, based on their daily needs and experiences, propose products they could use every day. Furthermore, let users (with some help if needed) develop their prototypes. Moreover, let the same users test their prototypes with their patients. Based on what they see work and not work, they can update their

products. No big/famous experts or grand theories here, just common sense trial and error, and build "appropriate" solutions, and scale the ones that succeed.

The primary intended user community is that of Care-givers. However, this approach can also be used by researchers, neuroscientists, nursing practitioners, social workers, etc. to quickly formulate their hypothesis and develop prototypes for testing.

An example of this approach is the way we use Excel. It stills need some basic learning, but now all of us (pretty much from all types of professional backgrounds) use Excel to solve our own problems. The way we encode formulas/rows/columns may not produce a nice looking report, but it does solve the problem we have in a rather quick manner. And we can change it as much as we need.

## **5. Journey Ahead**

We embrace the following ideas:

- Democratization of programming – that building computation-based solutions should be accessible to all and not just the programmers.
- The spirit of DIY (do it yourself) and Makers – enable everyone to exercise their creativity, build things, test, and iterate to improve.
- The challenge of building toolkits in a formal way to enable end-users create/compose solutions they need.

We are building a technology platform based on these ideas. Our goal is to enable care-givers (informal, formal), volunteers, researchers, nurse practitioners to develop mobile app solutions for their care-receivers.

Beyond building tools and technology, we are working on solutions to overcome the following four challenges:

- i. Finding solutions that work - the "solutions space" requires much experimentation.
- ii. Make it affordable across all social-economic classes, accessible everywhere.
- iii. Develop and deliver in a self-sustaining model - grants/foundations can only help so long
- iv. Scale to have a global impact

Addressing these challenges is critical to assuring broadest adoption and global footprint. To find "solutions that work" we propose using the user-as-developer or the organic evolution model. Basically enable users, researchers, practitioners to develop solutions they find useful. Users can develop patient to patient customization. Users in different geographical and socio-economic groups around the world could develop localized solutions for the same problem. Our choice of mobile computing platform as a delivery vehicle assures an increasing affordability as cost for mobile platforms drop. Global scale-up will be enabled by region-by-region localization of solutions, Developing a self-sustaining model is certainly a challenge and we are exploring various options. We are particularly inspired by the Aravind Eye Foundation model to allow people to pay what they can but assure that everyone gets the same quality and value irrespective of what they pay (<http://nyti.ms/U0BfBC>).