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5 mHealth Hope or Hype

Experiences from Cell-Life

Peter Benjamin, Cell-Life

Introduction

We are a social species – since humanity first evolved we have wanted to communicate within our family, community, clan, and more recently within our nation and globally. To communicate with everyone has been a dream in many cultures (for example, the Tower of Babel) and the ancient Greeks believed only the gods could express themselves so all could hear (it was called the weather).

In the last century, our species learned how to do rapid mass communication with radio, TV, and mass-circulation newspapers. In the last couple of years for the first time we have mass interaction. Today, in countries like South Africa, where 90 per cent of youths and adults have a cellphone (World Wide Worx, 2010), almost anyone just about anywhere can communicate with nearly anyone else, immediately and at a low cost (relative to any other way of doing this). This is extraordinary; it has the potential to transform how society is organized. We are just starting to explore what this means – many clever people have learned how to make lots of money. How can this be used to promote people making better choices around their health (part of what is known as Behavior Change Communications)? Well, I am not sure yet; and this is the story of the first steps of Cell-Life exploring what is possible with this new technology.

Cell-Life beginnings

Cell-Life is a not-for-profit company (Section 21 in SA law) based in Cape Town, South Africa, which develops open-source computer systems to support the health and HIV sector. This chapter describes the evolution of Cell-Life over a decade, and then gives some reflections on the hope and hype of mHealth.

Cell-Life started as a research project at the University of Cape Town in 2000 when two academics, Professor Jon Tapson and Dr Ulrike Rivett, decided to explore ways that electrical engineering could be used for social good. They were soon joined by Dr Jevon Davies of the Cape Peninsula University of Technology.

The first project in 2001 was a simple system for home-based carers (who support around a dozen AIDS patients each) to report back to the clinic on the patients' conditions. This system worked quite well at the Hannan Crusaid Clinic in Gugulethu (a township around Cape Town) run by the Desmond Tutu HIV Foundation (DTHF), the HIV clinical research center in Cape Town. However, the team learned that not only engineering factors matter. After the first week of the project, when the carers (who were all women) were asked how it was going, they said that they did not like cellphones. The Cell-Life team had bought good quality phones with the right technical specification, so they were surprised to hear this. In 2001, cellphones were not common, and the carers felt nervous carrying the big cellphones on the street and in public transport. After a discussion, they asked for cellphones small enough to hide in their bras. This was something the mainly male Cell-Life engineers had not considered.

After receiving funding from the Vodacom Foundation and others, in 2004 Cell-Life set up as a separate nonprofit organization. Cell-Life's second main product was a database system to assist pharmacists in dispensing anti-retroviral drugs (ARVs). The DTHF was one of the first organizations to provide ARVs which they dispensed from their main office at Groote Schuur Hospital which were delivered to township clinics for the patients to pick up. It was difficult to keep track of who received which drugs, therefore the request to develop a system for tracking the medicine. This became the 'Intelligent Dispensing of Anti-Retroviral Therapy' (iDART) system, which was installed first in clinics in the Western Cape, then in North-West province, then nationally. In this process, we started learning the complexities of working inside the health system – this was before there was comprehensive ARV access, and there was a great deal of politics around the HIV program. While pharmacists tended to like the system as it simplified their work, it was difficult to get people higher-up in management structures to make decisions. It took us several years to work the best way to engage with the health system, which was made much easier when we employed a medical doctor, Dr Sikki Noor Mohammed, who knew how the system worked and who to talk to.

Cellphones for HIV

I joined Cell-Life in 2007. Since 1990 I had been working in what became known as 'Community Informatics', the use of information and communication technology (ICT) for community development. First, this was in my home country, the UK, with Poptel, GreenNet, and the Manchester Host (a municipal email and bulletin board system in the early 1990s). In 1994, I moved to South Africa and worked in several organizations trying to use ICTs to support the social change in the newly liberated

South Africa. My PhD studied the efforts to establish telecentres. My thesis was largely a catalogue of the many technical, organizational, and financial ways these community ICT projects failed. It was very difficult keeping a center with a few PCs working in dusty remote areas with poor electricity, a community where very few people knew how to use computers and there was inadequate money to keep the equipment functioning. The people who benefitted were the few who learned computer literacy, and then left to get jobs in the cities. What we thought were local development projects in practice led to the best and brightest leaving the area (though they often sent money home to their families).

I was a slow learner. It took me about a decade to notice that about half the people in the village around the telecenter already had a cellphone, which compared with a PC had much better connectivity, worked more easily, people were much more comfortable to use and was accessible in a way that the telecenter would never be.

As I started to see the potential that cellphones could have, the job as general manager of Cell-Life became available. In my first few months, I asked of my contacts in the ICT and telecommunications field *'Who was doing HIV communications?'*, and all the people I was meeting in the AIDS sector *'Who was using cellphones to communicate?'*. To my increasing surprise, I learned that no one was. This was confirmed for me at the National AIDS Conference in June 2007 when I spent two days walking around the fifty stands in the exhibition hall asking all the organizations if they were using mobile tech in their communications: they were not, though half of the organizations expressed interest.

With some funding support from Vodacom and also the RAITH Foundation, we started the 'Cellphones for HIV' (C4H) project in 2007 as an attempt to introduce the HIV sector in South Africa to the use of mobile technology as a means of communicating within organizations and between organizations and their constituency. A first stage in the project was to develop the technical systems and gain operational experience. This took longer than we hoped – about a year and a half. While the techies were building an SMS engine we called 'Mobilisr' (together with a partner organization, the Praekelt Foundation), during 2008 we became a part of the wider HIV sector, learning the communications and clinical needs of the myriad of organizations, and as we were the first group talking about mobile communications and HIV, we were offered a seat on the Communications Task Team of the South Africa National AIDS Council (SANAC), which was a great place to understand the sector.

By 2010 our technology capacity included: SMS (broadcast out, and IN with keywords); USSD (basic text menus that all GSM cellphone can use that allows simple information retrieval and data collection); MXit (a massively popular cellphone instant messaging system used by over 20 million people

in South Africa, especially youths, and we provided the HIV content on this); Location Based Services (knowing where a cellphone is for ‘*Where is my nearest something?*’ services); Please-Call-Me (a means for someone with no ‘airtime’ to ask a colleague to phone them back – which is the only free way to send a signal from a cellphone which we use for people to subscribe to services at no cost) and Cellbooks for downloading large volumes of text to a cellphone.

These technologies were used in various ways, to meet the needs of our different partners. Cell-Life was learning how to apply the tools to meet health and social objectives. The tools were used to support different areas of HIV and health communications, including:

- 1 Mass communication for prevention with over 2.5 million SMSs sent to around 300,000 people;
- 2 Information for positive living (via SMS, USSD, and MXit);
- 3 Linking patients and clinics (adherence and appointment reminders, mainly using SMS);
- 4 Text counseling (we linked MXit with the National AIDS Helpline, so people could have ‘text-counseling’, and there have been over 21,000 counseling conversations since September 2009);
- 5 Organizational capacity building (providing subsidized or free SMS and USSD services to over 100 government, NGO, and community HIV organizations);
- 6 Monitoring and evaluation.

mHealth grows up

I was lucky enough to attend the Rockefeller Foundation Conference in Bellagio in August 2008 that started to crystallize the field of mHealth. It was exciting to learn from many others and feel that a new field was coming together (Atun and Sittampalam, 2006; Kaplan, 2006). After that workshop, we started seeing much of our work using mobiles in the HIV sector as part of mHealth.

In the last few years, there have been several other organizations in South Africa involved in mHealth projects, including GeoMed, the Centre for Scientific and Industrial Research, the Medical Research Council, Praekelt Foundation, Stellenbosch University, Right To Care, and the Reproductive Health Research Unit (RHRU). Most of the projects were fairly small scale, with all of us trying to find evidence to convince the government or a donor of the importance of mHealth.

However, the environment changed dramatically in mid-2010 when the National Department of Health received 15,000 good quality cellphones as part of the Universal Service Obligations of cellphone companies. During 2011, the rollout of two cellphones to all 4,300 public health facilities would begin. After a decade of largely failing to get an internet computer in each facility (today only around 1,500 of the 4,300 facilities have a working email address), in the next few months there should be the first comprehensive health informatics network throughout all facilities. The first thing the Department of Health want to do with this is to have a cellphone-based reporting system of HIV counseling and testing (it was a high priority to test 15 million people for HIV in 2011). After a tender procedure, Cell-Life, with our partner the Health Information Systems Program, received the contract to implement this in late 2010. This is definitely bigger than other projects we have done before – training 14,000 people at around 7,000 public and private health facilities. I am confident we will be able to deliver, but nervous to realize the new scale we are working at. Be careful what you ask for – you just might get it!

There is currently great attention around mHealth, almost a feeding frenzy. The mHealth Summit in Washington, DC in November 2010 showed the wide range of organizations involved in this new area with 2,500 people and dozens of organizations and projects (Mechael, 2009; Vital Wave Consulting, 2009; Cole-Lewis and Kershaw, 2010; Mechael, Batavia, Kaonga, Searle, Kwan, Fu, and Ossman, 2010). In particular, data collection systems, SMS messaging, and smartphone apps were everywhere. However, there was very little evidence. There were a handful of projects that actually could prove medical benefit through randomized controlled trials or similar; almost nothing that had gone to scale – Text4Baby (Centers for Disease Control and Prevention, 2010) and the TRACnet clinical reporting in Rwanda (Svoronos, Jilson and Nsabimana, 2008) being about the only examples – and absolutely no examples of a clear business case or serious health economic cost-benefit analysis. MHealth as a field is just emerging. Probably there will only be two or three years of such attention: the many overhyped ideas will fade away, while the really useful applications will not be called mHealth – it will simply be the obvious way to perform a particular task (just as there is not a Stethoscope Society – everyone can see it is the appropriate tool and so uses it).

Great – so what?

Did any of this have any effect? Just counting SMSs is not evaluation. At the organizational level, many organizations working in healthcare and HIV are now using mobile technology. On the World AIDS Day on December 1, 2008, and 2009,

SANAC asked us to use many mobile tools (broadcast SMS, location-based services to find local events, the Mxit-text counseling, and USSD menus for information), and they now consider cellphones as a channel for all communications such as TV, radio, and newspapers. To get a better assessment of the impact of these tools, we have run some formal studies (funded by Right To Care) into various applications.

One study tested whether SMS support messages can improve the outcomes of prevention of mother-to-child transmission of HIV (PMTCT). This was a randomized trial at a maternity hospital in Johannesburg (Coronationville Hospital) with 386 HIV+ mothers who (after informed consent) received SMSs for ten weeks after birth on various topics: Reminders to give babies HIV-prevention medication; encouragement on exclusive feeding; appointment reminders; new motherhood tips, and other positive living messages for those who were newly diagnosed with HIV. The study finished around August 2011, and preliminary results so far show a significant increase in the percentage of mothers who take their babies for testing at six weeks (58 per cent of those not receiving bring their babies in comparison to 74 per cent of those receiving SMSs; $p < 0.001$). But proper data will only be available on publication. Surveys of those who received SMSs indicate that they are appreciated and are seen as supportive and informative. Some mothers indicated that the SMSs helped them to accept their HIV status.

In another study called 'SMS to Test', we examined whether a series of SMSs giving information and encouraging people to take HIV tests would result in their testing. The SMSs dealt with common barriers to testing (as identified in the literature), and provided referral for where to get help with these issues. We also had two kinds of messaging: 'informational' content with HIV statistics and public health announcements; and 'motivational', which talked about taking control of one's life and respecting loved ones. Over 2,500 people were enrolled, and divided into groups: group one received no SMSs (the control), group two received three SMSs with 'informational' content, group three received ten informational SMSs, group four received three 'motivational' SMSs, and the last group, group five, got ten motivational SMSs. After the SMS campaign, recipients were surveyed to see whether they had tested for HIV, and whether the SMSs had affected their decision to test. The only intervention that showed an increased rate of HIV testing was the ten motivational messages.

We have also set up a system for HIV 'text-counseling'. Since August 2009, Cell-Life has worked with LifeLine, the NGO that runs the well-respected National AIDS HelpLine or NAHL (Katz, 2004). We have built a technical link between Mxit and the NAHL so that people can have text conversations with professional counselors on any HIV issue. Counselors were trained to provide counseling via a web-based Instant Messaging application. By January 2011, around 24,000 conversations had

happened and we are assessing its effectiveness. Users are surprisingly revealing things such as their HIV status and sexual behaviors. It is also clear that people still need basic information on HIV (like whether it is transmitted by kissing, or the fact that with medication you can live a long life). Anecdotal evidence from the counselors indicates that they can provide as much meaningful counseling in one two-hour session as they can in a week of telephone counseling. One reason for this is that they can have multiple conversations at the same time, and they have many fewer hoax calls. They have also indicated that mobile-chat counseling affords the client a degree of privacy not possible with telephone counseling: with the latter the counselors often hear background traffic noise (from public telephones) and clients using 'bland' language (not mentioning HIV), whereas on mobiles, clients can text-chat from anywhere with greater privacy. Cost is a major factor in the popularity of the service and its potential for scale-up and rollout in other countries. A counseling conversation using mobile voice costs the user US\$1 in the region (for a four-minute call); a similar conversation on Mxit costs less than US\$0.01. This provides a means for organizations to provide low-cost call center services via text counseling.

To date, Cell-Life has run various cellphone-based systems that seem to be liked by the users, but we are just beginning to be able to show any direct medical benefits.

What's different about mobile?

What is unique to mobile about these applications? Over nearly ten years, Cell-Life has learned to use mobile communications in different ways. Our first projects were around data collection for healthcare workers, and then we started providing services to patients. We have explored using the tools in different ways – from simple information reminders (for example adherence reminders), to emotionally supportive messaging seeking behavior change (for example the SMS to Test study), to two-way interaction (such as the National AIDS Helpline text counseling).

We have learned that as well as simple information, mobile technology can provide significant emotional support (Mefalopulos, 2008). The SMSs sent in the PMTCT mentioned above were valued: when asked why she would recommend the SMS, one woman said, *'Because it feels like whatever heavy you carried on your shoulders, that it actually becomes and feels much lighter.'* When asked whether the SMSs made the women feel better, various responses were, *'It made me believe that all will be ok'*, *'It gave me strength, I just felt better since I know that I am not alone and that you people also care about us and you know what we are going through'*, and *'Having a new baby is very stressful but by getting these*

SMSs it always made me excited.' Compared with most health infrastructure of buildings, equipment, and trained staff, cellphone messaging is a cheap and easy intervention – yet it can have a real impact. A mobile phone is a very intimate medium – people usually keep it on their person, and it can be a very useful tool to support people through difficult times.

Mobile allows interaction to support other forms of communication (such as TV, radio, print, and mobile) where messages from other media are extended via mobile, or where interactivity via mobile is added to traditionally 'one-way' campaigns. This is one of the areas in which cellphones can greatly strengthen health communications – allowing people to 'talk back' to broadcast media. Behavior change communication is most effective when there is a dialogue rather than simply a one-way flow of information. However, broadcast media are very poor at allowing interaction – radio phone-ins or letters to the editor do not provide a meaningful one-on-one conversation. Cellphones can be used to allow people to interact with the TV or radio communications (Winchester III, 2009). For example, after a program on a given topic, viewers can be encouraged to SMS in their comments; vote in a poll; join a subscription list by sending an SMS (or Please Call Me) to a number; or find their local clinic or health facility by an SMS/Please Call Me to another number. If they want to discuss the issue, they can go to an Instant Messaging chat room (such as through MXit); or if they have a serious issue they can seek counseling. This can allow the wide reach of the broadcast medium to be the first stage of an ongoing interaction.

Mobile also allows narrowcasting, where a message is targeted at the small population to whom the message should be relevant. If the demographics or interests of people are known, then mobile phones provide an easy way to reach this population (as would an email if they have the facility, or a normal letter if there is the time). For me, the big news is not that this technology is mobile. The main issue is that almost everyone has one – cellphones are nearly ubiquitous in countries like South Africa.

If you do not have medical aid, live in a rural area, and are feeling unwell, you have three choices. Firstly, you could do nothing and hope it gets better (which is actually what happens in most cases). Secondly, you could go to the public clinic (either an hour's walk or expense of bus/taxi) with all the inconvenience of travel, childcare, time off work (if employed). There, you wait for a few hours to then get five minutes of attention from a hassled, overworked nurse who *may* diagnose you correctly, and possibly has the appropriate medication and then there is the long trip home. This has taken most of a tiring day (and remember, you are already feeling sick). The third choice is to go to a traditional healer, who probably lives close to your house, will probably be nice to you, and will listen properly to

what you have to say. The human interaction between a caregiver and patient is therapeutic itself and at the heart of curative medicine. By some estimates, there are ten times more traditional healers than registered health professionals in the country. This is usually discussed in terms of traditional versus educated world views; but it also is a measure of how inaccessible the conventional health system is to the majority of people in these contexts. There is a possibility of using mobiles to increase access to scientific healthcare through near-universal access to primary health information, access to triage counseling to give an indication of whether you need to go to the clinic, and widespread promotion of preventative health.

As Clay Shirky has said, 'These tools don't get socially interesting until they get technologically boring' (Shirky, 2009). It is not the few thousand iPhones in South Africa that will make a major difference – but if we can find a way to turn these electronic-connected devices in the pockets of 90 per cent of youths and adults into means of accessing a range of medical services that could transform healthcare. However, while cellphones provide a means of reaching a very large number of people, it must be remembered that there are a significant number of people who do not have access to this technology. Health communications that assume universal cellphone usage will leave out the people who are likely to be the most disadvantaged – which can lead to a form of 'double exclusion'.

Different from other forms of telemedicine or electronic health (eHealth), mHealth can talk about aspects of healthcare beyond just the curative (fixing people when they know they are ill). Because a majority of people can use these tools regularly in their lives (and not only when visiting a clinic), mobile tools can build health awareness, enhance preventative healthcare, and support well-being and overall wellness. This is a much wider agenda for technology in healthcare than ICT and medicine usually covers.

Cell-Life is currently working on ways to provide useful health applications through basic phones – 'smart apps for dumb phones'. These health applications could range from basic lifestyle services (such as losing weight, stopping smoking, doing exercise, and eating well), through general health information (for example health services, primary healthcare info), condition-specific services (such as adherence to medication, self-managed care for TB, diabetes, and hypertension), and health administration (booking appointments, receiving updates), to medical consultations and counseling.

We have just started to learn how to use this new technology. As cellphones are in the hands of the great majority, mobile technology provides an opportunity to increase equity in the provision of quality health services. There is a huge amount of work to do.

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