Sharedcare: Design Oriented Innovation Scan of Informal Health

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design oriented innovation scan of informal health
A thesis submitted to the School of Design, Carnegie Mellon University, for the degree of Master of Design in Communication Planning and Information Design.

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Shared Care is a paradigm shift that addresses informal health, which probes into health for the healthy and care that is non-institutional. A shift from ‘my health is my problem’ to informal care systems based on proximity and trust. The community is mutually responsible for the health of its members and shares common goals of wellbeing.

A growing population in urban contemporary cities, as they traverse through different phases of life are not foreseeing the effects of place, social support and care in their long term wellbeing. With the lack of faith in a healthcare system that equates good care to insurance, the opportunity is to move away from problem & symptom-based fee-for-service care to focus on preventative care that lies outside of the current system in the US.

The hypothesis that guided the research considered the intersection between health and social as an alternate / complimentary approach to preventive care as understood today. By using design as a research tool, rich narratives of personal stories related that enabled in outlining the potential to shift from the ‘me’ to the ‘we’ paradigm of one’s wellbeing. Disclosing emergent spaces where service design can be used as an entrepreneurial approach to envision solutions that enable informal support systems between weak tied individuals based on physical proximity.

Motivations, infrastructure and characteristics of designing for these emergent spaces in housing, mobility, work life, food systems and sociality, were identified as holistic components of overall wellbeing. By applying the ‘we’ paradigm framework to the design of services we can further investigate the transition towards health related sociality within communities.
To Ma, in your strengths I have found mine. For your infectious laughter and sharing cups of tea over Skype for the last two years.

To Pa, for always being right.

To Misba, for always challenging my way of thinking.

To Cameron Tonkinwise, for making coming back to grad school for the second time absolutely worth it. And also, a memorable optimally functional advisor-advisee relationship.

To Dan Boyarski, for giving me the opportunity to teach and reminding me constantly of why I love design.

To Mark, Christiana, Nicolas, Jung, Gilbert and Brynn for your moral support, friendship and hugs.

To Gambitto and their blind faith in what I do.

To all my colleagues at CMU for being a wonderful small family.

And lastly,

To Ram, for your tireless patience, persistent belief and love.

Everything happens to everybody sooner or later if there is time enough.

- George Bernard Shaw
each of us is responsible for everything and every human being

– Dostoevsky as quoted by Simone de Beauvoir
Now, what about the future? In this matter I would like to share with you the insight of my good friend, the distinguished Argentinean ecologist Dr. Gilberto Gallopin, who has proposed three possible scenarios.

Scenario one, is the possibility of total or partial extinction of the human species. The most obvious way for this to come about would be a nuclear holocaust, which, as we know, is based on the principle of Mutually Assured Destruction.

Scenario two is the barbarization of the world, a new way of turning humankind into barbarians. Part of this scenario will be the resurgence of the repressive regimes cooperating with the wealthy bubbles and imposing further hardships on the poor.

Scenario three presents the possibility of a great transition—the passing from a dominant rationality of blind economic competition and greed to a rationality based on the principles of sharing and solidarity. We might call it the passing from a Mutually Assured Destruction to an era of Mutually Assured Solidarity. But can we do it? Have we the tools, the will and the talent of constructing a mutually assured solidarity? Can we overcome the stupidity that keeps such a possibility out of our reach? I believe that we can, and that we have the capacity. But there may not be too much time left.


As opposed to Maslow’s hierarchy of needs simplistically depicted in a pyramid, Max Neef’s human scale development [1] addresses needs as an organic coexistence of being, having, doing and interacting. Where the foundation of subsistence lies in physical, mental and social well-being. There isn’t any hierarchy of needs but what becomes evident from the interrelations is that social setting and interaction is a fundamental satisfier in the sustenance of human beings. The stupidity of the way of life today as he rightly identifies has strained our understanding of physical and mental well-being by equating health to economic stability and in return the choice that it provides in the autonomy and control of one’s lives. Where social support and trust is no longer seen as a valuable currency of existence.

The following theses is an inquiry of health as a social concern. If interacting and being in the world with ‘they’/‘others’ is a fundamental human need then how can we as creative practitioners and critical thinkers re-imagines the world that affords solidarity in the maintenance of our wellbeing. The current landscape of the maintenance and repair of one’s health oscillates between disjoint value systems of individual care / self care practices and institutional / expert care. From ‘my health is my problem’ to in the situation of breakdown seeking expert help / care. The ‘in between’[2] space between self help and institutional care is what the research further explores with respect to the role designers and creative practitioners can play in considering new frameworks to enable transition towards social health behaviours that would build stronger communities that are based on physical proximity between weak tied individuals.

prologue

how to read this report?

The report consists of four sections:

**Introduction**
- Sets the background, context and relevance of this particular type of research.

**Part 1**
- Sense making and mapping the problem space.

**Part 2**
- Projecting a future in the identified problem space through design scenarios.

**Conclusions**
- New frameworks for future applications.

Within each section are key questions that are highlighted on the left-hand side of the book. These questions have been key moments of insight, reasoning and understanding of a very complex and messy space of research that I have constantly found myself wading through. They will also help hold a continuous narrative of my research process.

References are cited on every page.

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**Type of Research**

Design as a research tool to provoke participants and industry experts to respond to future scenarios of care and reflect on current practices. Generating frameworks to breakdown and gather insight into the factors affecting accepted norms of individual health.

**Method**

Mapping correlated parallel practices and systems of individual and institutional care. A scan involving understanding current precedents supporting the need for alternate approaches to long term systemic commitment to social health.

**About**

The in between space between individual care and health practices and institutional maintenance, support and care. Non expert based informal human network of support and care in the enabling of healthy behaviour towards oneself and the community based on physical proximity between weak tied individuals.

**Definition**

Shared Care is a paradigm shift, which addresses health for the healthy and care that is non-institutional. A shift from 'my health is my problem' to informal care systems based on proximity and trust. Where the community is mutually responsible for the health of its members and shares common goals of wellbeing.

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**sharedcare**

design oriented innovation scan of informal health
content

Background 36
Introduction 37
Significance 31
Innovation Scan 23

Part 1 - Understanding a messy space
Approach 25
  hunches 27
  exploratory research 29
Findings 36
  New definitions 43
  Enemies of Shared Care 44
  Problem framing & Emergent space 45

Part 2 - Projecting a future in Shared Care
  Designing for Shared Care 47
  Personas 49
  Disclosure through design - Experiments 51
  Key Findings 53
  Framework to adapt Shared Care 55
  Mapping insights 56

Conclusion 77
  Future directions 79
  Emergent space 80
Epilogue 84
Bibliography 86
introduction

A techno-centric approach to solving the rising health concerns of the west may seem like the trending momentum of the present, but it cannot be viewed as a compelling mechanism to cope with commitment to long-term health and wellbeing. Historically and culturally unlike the east, the west is known to herald individuality and nuclear upbringing to fuel its principles of a thriving economy. Even though the west may seem like the trending momentum of the present, it is unclear what the larger implication of that would be. Recognition that we need to move away from problem & symptom-based fee-for-service care and focus on preventative care and how people can live better with long-term maintenance and commitment to health is seen as an individual’s prerogative and outcome of a complex healthcare system that equates social health as an equal component of ones holistic wellbeing along with physical, mental, environmental and spiritual components. Social support is not connected to any financial institution or governing systems in the day to day maintenance of ones health as well as when something really goes wrong ie. sickness. It is a well established fact that family ties, friends and peer relationships that comprise social health are an equal component of ones holistic wellbeing along with its physical, mental, environmental and spiritual components. Social support is not connected to any financial institution or governing systems that could possibly have adverse effects on ones health. Hence, between individual care that is based on motivation, governing systems that could possibly have adverse effects on ones health.

Lack of faith in the system - Due to its continuous sky rocketing costs and overall unfulfilled expectations, people seem to become the custodians of ones health future there is a growing lack of faith in the institutions in the US. After a dysfunctional government becomes the custodians of ones health future there is a growing lack of faith in the system cannot support/ provide. [8]

Social network studies have proven that obesity runs in social circles, people are born into social networks that support healthy behaviours, but it cannot be viewed as a compelling mechanism to cope with commitment to long-term health and wellbeing. Historically and culturally unlike the east, the west is known to herald individuality and nuclear upbringing to fuel its principles of a thriving economy. Even though the west may seem like the trending momentum of the present, it is unclear what the larger implication of that would be. Recognition that we need to move away from problem & symptom-based fee-for-service care and focus on preventative care and how people can live better with long-term maintenance and commitment to health is seen as an individual’s prerogative and outcome of a complex healthcare system that equates social health as an equal component of ones holistic wellbeing along with physical, mental, environmental and spiritual components. Social support is not connected to any financial institution or governing systems in the day to day maintenance of ones health as well as when something really goes wrong ie. sickness. It is a well established fact that family ties, friends and peer relationships that comprise social health are an equal component of ones holistic wellbeing along with its physical, mental, environmental and spiritual components. Social support is not connected to any financial institution or governing systems that could possibly have adverse effects on ones health. Hence, between individual care that is based on motivation, governing systems that could possibly have adverse effects on ones health.
Healthcare in the United States is a mess. Technically, a “mess” is a complex set of problems with inextricable interdependencies. The overall system of healthcare—from services to payment to policy—has grown so complicated that a redesign of its components would not change the system substantially. New design thinking is called for, yet where do we start? Designers have no access to the system levers, and most of our work today is aimed at making the components run better and safer.

There is a rich space ‘in between’ which relies on power of the people in our lives who are active participants and contributors in our health seeking behaviors. They could be neighbors, friends, colleagues, family and alternate social networks who need to be leveraged as complimentary care systems in our long term commitment to health and well being. In return reducing the burden on archaic institutional systems that treat individuals in isolation sickness based without considering the connected community they are a part of that could/should be prepared to provide care in the time of need.

Currently much of the human centered design application is implemented in mainstream healthcare systems like medical devices, home care for chronic ailments, prosthetics, neuroscience and support towards the elderly to name a few. As well as innovative applications in the individual health maintenance, efficiency and support with fitness monitors, wearable technologies, sensors and some around individual behaviour change. Although incredible contributions continue to be made they are all addressing existing immediate problems that have been an accumulated result of outdated institutional practices that actually need rethinking. The healthcare debate no doubt is messy and the goal of this research is not redesign the healthcare system, but it is to identify to bring to the forefront the before mentioned ‘in-between’ space which needs the critical eye of design to reimagine complimentary care systems that could be the foundation of the beginning of transition towards long term commitment to health that is no longer left at the onus of an individual but as collective understanding of new practices and routines in the social health space.

There is a need for complimentary pro social but non-techno expert centric approaches to helping people begin to transition towards new lifestyles that are built on the foundation of community support and informal place based care towards ones health. By investing and committing in people and place can we build alternate support systems of trust where technology is seen as a means and not the end solution?

Design for Care: Innovating Healthcare experience by Peter Jones
As designers is our prerogative to not only use human centered design methods to tend to wicked problems of today but also use design as a research tool to disclose new worlds of possibilities where we reimagine alternate practices that question and provoke age old systems that have not been questioned due to its financial power. This research is a step back from the identifiable processes of design and a higher level scan of a very complex space. Through the activity of gradual scanning across the vast territory of individual health seeking practices to influences of institutional systems, it begins to question current languaging and its implications towards design. Along with constantly mapping existing practices that are monotonous and weak signs of anomalies that are trying to break away from the existing norms of individual health. By analyzing current behaviours through the lens of the social it builds a case for the rich in-between space of informal health practices that are non-expert non-social. In order to trigger a gradual transition towards the informal health realm it identifies new roles of designers who project a future which may seem unacceptable in the present. A future where one would invest in micro community based social networks between weak tied individuals who become an integral part of ones health seeking routines and practices.

The significance of a research of this undertaking is to help clarify existing language and its implications and dogmas around changing health behaviours and using that to build frameworks for designers to better understand to propose alternate frameworks for new products, services and systems. With social health as its core value which could reshape the future application of preventative complimentary care.

**What is the future of preventive care?**
**What are current individual health seeking behaviours?**
**What role does social network play in the maintenance of ones health?**
**What is the influence of the healthcare system over people’s understanding of their health?**
**What could be complimentary approaches to preventive care of the future?**
**Can there be peer to peer based support networks that act as a buffer between self care and insitutional care?**
The research is framed as an innovation scan deliberately due to the vastness of the terrain of health it attempted to cover. The intention of the thesis from the beginning was not to reach to a final solution to the current problems of maintaining good health and the implications of a complicated healthcare system. But, it is to critically question the interrelations and interactions between the two, the existing language and values associated with expert and non-expert care and scanning for emerging opportunities to rethink the norms of today.

The intention of the scan is for it to be used by designers and key stakeholders in re-imagining services and systems of the future of the intersection of health and social. The frantic need for an alternative if not complementary health systems calls for new approaches in tackling the convoluted value system that has been fueled by economic interests of private enterprises. The scan spans across the spectrum of individual health and care practices towards institutional care systems. The middle ground between the two which is the buffer space or the in-between space is what the scan opens up for discussion and inquiry as the ‘we’ paradigm of complementary health systems which is non-expert driven but based on social ties, not necessarily related.

The infrastructure and technology today already afford immense sociality in the digital world. The role of designers and stakeholders today is to identify emerging spaces of interventions, such as in this case the domain of informal health and reconfigure existing infrastructure and technology to open up new practices that lead to long term adoption and behaviour change for the greater good of humanity.
part 1
understanding
a messy space
Definitions

Health: The state of being free from illness or injury. A person’s mental or physical condition.

Wellbeing: A state of good health. A state of being comfortable, healthy or happy.

Wellness: Practice of maintaining good health.

Healthcare: The maintenance and improvement of physical and mental health, especially through the provision of medical services.

Care: The provision of what is necessary for the health, welfare, maintenance, and protection of someone or something. Serious attention or consideration applied to doing something correctly or to avoid damage or risk.

If one’s overall wellbeing is a combination of physical, mental, social, environmental and spiritual health then why is it that the definition of one’s health is the state of being free from illness or injury? The biggest concern of the role of the healthcare system today is expert maintenance, improvement and support in the time of a disease/sickness or ill condition of health. When the health of an individual breaks and one turns to the healthcare system, the reactive solution is to provide care to an individual but most often not considering the social support structures needed to cope with recovery. Health concerns today hence oscillate between disparate values between individual and institutional care.
exploratory research

The exploratory research phase covered interviews, literature reviews, surveys, and finding precedents of existing practices that are weak signs of alternate health behaviours.

Each segment of the exploratory research phase was designed to focus on inquiry within the spectrum of individual and institutional health practices. The user interviews focused on current motivations and understanding of health practices. What are people influenced by in maintaining good health? Do they have support systems that encourage them to stay healthy? What is their experience with the healthcare system? to name a few. The Literature and Survey study focused on Social support and networks of individuals and its application in known medical fields to understand frameworks that could be implemented outside the expert domain. A running list of precedents showing evidence of alternate products, services and systems establishing transition in smaller communities was maintained throughout the project to gauge a deeper understanding of the circumstances and need to seek newer approaches to wellbeing.

User research group

Millenials - The research is primarily focused on the understanding and practice of health in the US but participants across different cities in the world were interviewed to get contrasting views. The key user group that were targeting and interviewed were millennials (22-35 yrs), living in cities and transitioning through different phases of life. This particular user group was chosen as a sample set as they are right now at a point in their life where they are young enough to be still healthy but slowly making it towards the time in their life where some are beginning to show signs of deteriorating health due to lifestyle choices. Health is yet not the top of the list of priorities as they are still coping with transition. Specifically a few were people who had recently been diagnosed with a health condition and were recovering or coping with changing their lifestyle to live healthy. Hence, to get a deeper understanding of what might enable them to consider and begin to take long term health measures that are not necessarily driven by institutional pressures and individual motivations but alternative communal measures that could become a routine practice in the future.

Subject matter experts - Subject matter experts across the domains of government, non-profit and for-profit organisations who are actively involved in the healthcare sector.

User interviews, Literature & Survey, Precedents
research participants

31 participants. All living in cities.

Participant A - 34 yrs, Health Investment Banker. Recently went through surgery and has been making active changes in his life to become healthy. Lives with wife and daughter.

Participant B - 32 yrs, Marketing at ‘Formoms’. Active and extremely health conscious. Lives with wife.

Participant C - 32 yrs, Graduate student. Active and naturally health conscious. Lives with husband.

Participant D - 25 yrs, Graduate student. Recently underwent a paralysing illness. He has started running and actively changing his lifestyle. Lives with roommates.

Participant E - 25 yrs, Consultant. Few years ago went through back surgery. Maintains a healthy lifestyle since then. Lives with roommates.

Participant F - 27 yrs, works in the non-profit sector. Struggles to maintain a healthy lifestyle. Although naturally inclined to not put on weight. Lives with roommates.


3 experts.

Expert A - Worked for a web-based service that provided medical information to everyone.

Expert B - Works for the mayor’s office. Focus on healthcare policy for the city.

Expert C - Runs a non-profit for caregivers in the city through workshops and information sessions.

research methods

The research exercises and questions were designed around word associations, card sorting, social network mapping and walk-through of speculative designs. The methods used were to gauge responses under the following categories:

1. Understanding of terminologies Health, Wellbeing, Healthcare, Care and Wellness

2. Individual practices of being healthy. Motivations/Challenges/Influences/Triggers / recent lifestyle change or illness

3. Key social relations in terms of sharing health and care

4. Social network with respect to geographical proximity and trust

5. Prioritising the different aspects of health

6. Experience with the Healthcare system and their opinions on role of doctors and institutional care

7. Speculative provocations of possible future scenarios of shared care. Group diagnosis, Care pact and Trust Insurance.

7 participants. All living in cities.

Expert B - Works for the mayor’s office. Focus on healthcare policy for the city.

Social network mapping: On a matrix they plotted their close network of relations from friends, family, acquaintances and colleagues and talked through people they considered close and trusted in a close physical proximity.
lis of choice scientific knowledge is taken to be a growing collection of facts that gradually increase in certainty. Professionals need to know these facts.

With the relevant facts laid out, someone has to determine the value of various possible courses of action. What might be better? A pen or a pump? Tight or mild regulation? This insulin or that other? Once a decision is made, providing or implementing the chosen technique is a professional task again. But as making the decision is a matter of balancing values, there is no particular reason why doctors or nurses should be doing this. Since treatment interferes with the life of patients, if it is the values of patients that should count most, financi-

Social Capit and Social Support
“social relations of mutual benefit characterised by norms of trust and reciprocity”. In this sense, reciprocity relates to the assumptions and expectations underlying the obligations which people, groups and institutions have to one another.

Social support is the primary buffer whilst recovering from any illness or chronic disease. In many instances support has been reported as a critical stress buffer when dealing with daily to day concerns of life. Studies have shown consistent access and engagement in an active social community also increases chances of early detection and action towards many unnoticed psychological symptoms of depression and loneliness that if gone undetected many times leads to the build up of chronic fatal diseases. Hence, having buffer systems within friends, family, neighbors, co-workers and multiple networks can be a helpful and life changing release towards holistic health 

The role of the designer hence is of someone with a hunch and the sense of an anomaly and by actualizing it through her/his entrepreneurial activity bring to the world what a perceived future would look like. These could be experiments that then become artifacts of provocation and research insights to get a deeper understanding of either resistance or acceptance of perceivable change that could lead to identifying concrete deeper problem framing within a vast space of intervention.

within the logic of care. And it is: in the logic of choice. But not in the logic of care. 

holding on to an anomaly as an anomaly is not easy to describe; it is a matter of constantly being sensitive to whatever oddity is happening in one’s life, in our case a matter of remaining sensitive to the fact that the entrepreneur’s work was not producing any concrete or abstract thing, but nevertheless he was working.”

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Mole, Marie Anne, Logic of Care, Amsterdam : Rodung, 2008, Print


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precendents
Existing research, services and products in the 'inbetween' space of social health.

Radical Redesign, Australia
Australian organisation researching old age care. Family by family / In health forward.

Care reflect, Australia
Australian Centre for innovation/rethinking scenarios.

Wellfare Review, London
Long at last. The big time giving grants to localised communities. Through collaboration and building trust within communities.

Ithaca Health Alliance, USA
Subsidised Insurance of collaborative care support to communities. Communities Self insure for Cooperative Healthcare.

Villa Breda, Finland
Rethinking organizing municipal services in cities based on wellbeing of the communities.

Planetree
Circles of Care was a project done at RCA which focused on the role of social networks in providing support to an individual through the different transitions of phases of life. It is here that the term 'in-between' space was used to define the gap between individual care/health practices and institutional care/health practices. The difference between expert and non expert care was established against the background of the current healthcare system’s healthcare costs and reactive measures of care.

Harvard Medical School
Shared medical appointments.

Peers for project
Support group for health and disease.

ITN America
Transportation alternatives for older people.

Making room
Designing an array of accommodating, desirables, safe and living for singles, shared households, and extended families, without the current restrictions.

People powered health
Project by public policy lab on collaborative care.

Lambert Collaborative, UK
Providing support through collaborative for mental health

Connect and do Lambert
Online platform to find out about things to do and people to share with in neighborhoods.

Coalition for Collaborative Care
Curate people with long term illness through peer support networks.

Time Banks
Sharing time as a reciprocal activity to give back in time.

Health Hacks
Health hacks where communities share with each other DIY solutions to problems.

Patients like me
Patients share data about their diseases or chronic illnesses with everyone. Through the exchange of data they share they are able to better cope with recovery.

Tattino, Finland
Urban health transformation platform.

IFTF - Institute of the Futures, Palo Alto
From the late 2000’s IFTF has been contributing towards research and innovation in the realms of future systems and scenarios of healthcare practices through their ‘Health + Self’ initiative.

What usually are funded programs by private organisations, the resulting forecast maps, wellbeing maps, future of managed care, booting up mobile health and wellbeing perspectives lean towards the sharing social component of health and wellbeing in the future. The insights from these mapping domains clearly affirms a shift that will gradually arise or we will be forced into where the intersection between health and social components of one’s life cannot be avoided in order to survive from economic unrest and exponential cost turn around. Not to suggest that financial strain is the probable reason to bend in this alternate direction but they do present already existing experiments within smaller communities that are exploring new ways of living and peer sharing to not only live sustainably but also maintain long term health through connected networks and support systems.

NESTA - United Kingdom
Across the other side of the Atlantic, Nesta is an innovation lab that is truly pioneering experimenting with community support and engagement in rebuilding and rehabilitating the elderly population in Lambert Hall, UK. They have been field testing multiple design interventions in the peer to peer support realm to provide scaffolding for an aging population. By engaging and training the youth in communities they are experimenting with building a support network that is collaborative and sustainable across generations. This lies completely outside of financial institutions like insurance and expensive medicare. Hence, the reliability is completely based on the motivation to continue getting better and growing their social network. Although their work in primarily focused towards the elderly, their methods raises questions around it’s application and scalability across different populations where based on the same intent contextually relevant services and systems could be designed.

Circles of Care - Indri Tulsian, RCA, 2004
Circles of Care was a project done at RCA which focused on the role of social networks in providing support to an individual through the different transitions of phases of life. It is here that the term 'in-between' space was used to define the gap between individual care/health practices and institutional care/health practices. The difference between expert and non expert care was established against the background of the current healthcare system’s healthcare costs and reactive measures of care.
research findings

1. To the transient population health is not the top priority. They are coping with constant change and having to deal with stressful lifestyles.
2. As they move farther away from home their primary systems of social support are no longer in the same cities as them. Parents, school friends and relatives are no longer in close proximity to directly rely on in case of an emergency.
3. Emerging roles as caregivers. Millennials are soon realising their roles as caregivers to their parents. Considering most of them no longer live in the same cities, they are beginning to learn about what the future of their responsibilities might be like.
4. Building stronger social networks that are no longer limited to physical proximity. They make an effort to reach out and keep in touch with friends and family around the world. Digital tools like Facebook, Instagram, WhatsApp, Viber, Skype and Snapchat are all part of their day to day rituals of maintaining relationships of care.
5. Trust in selected social network despite distance. It is earned and built over years of knowing.
6. Slowly beginning to consider the value of place but still not completely committed due to the situation/stage of their life.
7. Balance between physical and mental health is key to a stress free and happy lifestyle. Maintaining work-life balance is very important to stay healthy.
8. Health Care system is really expensive and complicated - Those who had a bad experience with the healthcare system had feelings of fear, distrust and helplessness. They considered it was built for the privileged and people with money and the ones with no monetary support suffered the most. But those with good health continue to believe that as long as nothing goes wrong they don’t mind paying the price.
9. Insurance is a necessary evil - As there is no official alternative to combat the complicated healthcare system, they buy into it because they would rather be safe than sorry in time of a desperate need. Money is the only assured guarantee of trust than people at this point. One would rather pay and not worry about it.
10. Scope to re-envision preventative care and bridge the gap between cure and care - The way the current system is set up is only when something really bad or extreme happens with respect to ones health. There needs to be new ways of thinking about preventative care that is cheap and the fundamental right of every citizen towards healthy living.

The predominant theme that emerged from the conversations with the participants and experts is the latent unsaid understanding of the ‘me’ paradigm. The ‘me’ paradigm is the outcome of the influence of the current healthcare system and supporting infrastructure which leads people into an inward ‘me’ centric thinking around their health. When it comes to the everyday maintenance and support of their wellbeing it is understood that it is up to the individual to take care of themselves. The infrastructure and support are all directed towards an individual’s motivations and consciousness to act upon. Hence, it is not uncommon to find most people trying to maintain their health.

The way the current care system is set up, only in the situation of an illness/sickness/disease that one would resort to expert help/care. The rest of the time one would resort to self diagnosis/care or reach out to immediate family. The understanding of expert care in this US is predominantly ‘Insurance’. Which is also based on an individual’s ability to back it up with enough funding to pay for the obscenely expensive expert care. What becomes clear is that although there is a growing concern towards the maintenance and support of health, there is also the paranoia towards having no support in the time of emergency which leads to fueling the complicated healthcare system through financial incentives. This vicious two way fortifying of mislead values is what is making it harder for current system shapers and policy makers to break away from looking at the wicked problems from a fresh new perspective.
self care framework

Active

Active are those who are aware of what needs to be done to stay healthy. They are intrinsically motivated to make the small changes in their life to keep up with a healthy routine. Most technology products and services are targeted towards the active archetype. These products and services need to work with these products in order to change actual behaviour.

Passive

The passive are an archetype in which a major chunk of today’s population falls under. They know they need to be healthy and are conscious of its implications but are not entirely motivated to adopt accepted norms of healthy practices. This could be exercising, running or eating healthy. Although they know that these are good for you, they are passive archetypes that suffer the most in terms of stress and lifestyle influences.

Indifferent

The indifferent are in most cases the archetypes that are most difficult to consider changing through existing design interventions. They are less aware and motivated because of which they make health choices and suffer problems over time. It is due to the indifferent cause that the list of systemic problems of rising healthcare costs are so severe as they are not invested in preventative measures.

Sporadic

The sporadic archetype are the motivated kinds but not necessarily motivated towards being healthy. It is the activity that motivated them to take action.

The framework helps gain a deeper understanding of why the current individual self care practices are so varied and rooted in their everyday routines. The framework is a collected summary of the interviews with participants, experts and literature that affirm the ‘me’ paradigm that began with a hunch about the current setting of health. By establishing the framework to understand the ‘me’ paradigm it also opens up opportunities to map existing products and services that are targeted towards individuals in the health segment. Fitness products and services can be better analysed once we view them from the lenses of these archetypes of users. It could also explain much of the problem with retention and considerable behaviour change that is so hard to achieve with respect to adopting health seeking behaviours.

The self care framework is the starting point to begin rethink existing behaviours. The next step from here was to analyse the individual frame from the lenses of external agents that often shape and support health seeking behaviours.
Care giving
“I know I should be taking care of my parents, I do think about it. But I am not there yet in terms of doing something about it, maybe because they are not in the same city.”

“I feel responsible for my wife and making sure she is happy and I am providing enough.”

Challenges
• Accepting the role of future care givers
• Distance from close family members and loved ones
• Work-life balance.

Social Capital
“My brother lives in the same city and I always have him to rely on for any personal or family emergencies.”

“My wife helps me stay healthy; she cooks meals for me and makes sure I get enough exercise.”

Challenges
• Investing time, effort and energy into building networks that are not long term
• Closeness is built over time and through sharing similar interests. Someone who has a stake in it
• Trusted support networks of people are no longer in physical proximity

Social Network
“I realized when my sister moved out I had to reach out to my high school community to make new friends.”

“I use running as a means of hanging out with my friends.”

Challenges
• Coping with change and uncertainty. Constant flux in urban living
• Struggle to maintain work-life balance and maintain healthy distances within networks
• Scattered social circle. Blurred boundaries with digital and physical networks

Preventive Care
Personal
Diet and exercise
Family doctor
Therapy
Quantified self

Challenges
• The current care system does not recognize social practices beyond the financial structure of the system
• Insurance as a trigger for fear
• Motivation and consciousness

The four predominant lenses of analysing the ‘me’ paradigm emerged from existing challenges and precedents faced in the everyday health seeking routines of individuals. These stood out as anomalies as they were all connected to people in their lives and not just themselves. The research approached these anomalies as opportunity seeking lenses that could be explored as an opening for design interventions.
Health outcomes are dependant on behaviours of individuals and the influence of the healthcare system today. The ‘me’ paradigm is situated within the individual behaviours outcomes. The research establishes new definitions based on a deeper understanding of the self care framework with respect to its relationship with institutional care and the in-between social care.

Informal Health is non expert driven maintenance, support and care towards one’s overall being that is based on the social support from one’s network of people preferably in close proximity.

Shared Care is the practice of informal health. It is the sharing of health with the community and its people through informal care systems based on proximity and trust. The premise of shared care is to enable investment in place and its people to building long term relationships of care. Hence, within the territory of health outcomes it is the bridge between self care and institutional care. A rich space that requires attention and needs to be tapped into to address complementary preventive systems of wellbeing that can leverage human capital and support instead of unnecessary financial systems that have no relation to one’s health.
problem framing & emergent spaces

Shared Care as a social innovation
How can design work to establish the current intersections between health and social as an alternative type of preventative care that would have implications on future healthcare policies and design of healthcare systems?

‘Place’ through connected people
Can the conception of ‘place’ be through the network of people? How can design enable commitment to build the social capital of a place in order to foster shared care and a sense of belonging whilst in transition?

Informal urban trust networks
How can design enable informal, proximity-based urban trust networks that make shared care an alternative to insurance? What role can design play in creating conditions of trust to enable frictionless care?

What is health for healthy and care that is non institutional?

Enemies of Shared Care

Logic of Choice and Expertise - In a system where the doctor and the healthcare system is trusted and considered to have the supreme decision making power when it comes to one’s health it is also a deterrent in terms of building complimentary approaches to health that are not necessarily expert driven. What is often not accepted is that not all aspects of one’s health require expert intervention. What is often not accepted is that not all aspects of one’s health require expert intervention. When it comes to everyday care and maintenance of one’s wellbeing it is social interactions and environmental support that leads to an holistic way of being. Most of the social interactions are ones in our immediate social network or physical proximity. Maintaining healthy relationships on that level is what enables reduce the stress and overwhelming burden of coping with the lifestyle changes of today.

Deppleted Social Capital - A greater amount of the population today is in constant flux and moving from one city to another. It is not uncommon to not know your neighbors in an urban setting and live secluded urban lives. In many cases as people have transitioned from one phase of life to the other they have moved further away from their families and fundamental support structures. It is due to which there is a lack of trust and paranoia around investing in new ties and relationships when the eventual move is always on the horizon as lifestyle transitions towards the new.

Emphasis on Privacy - The current setup of the healthcare system has created a looming myth around privacy of ones health data. The current insurance structures and healthcare providers have lead to myths around exploitation of ones health by pharmaceutical companies and corporations who are looking to make money. Policy makers and the government have further encouraged a closed system of managing and supporting healthcare due the economics involved in funding these programs.
part 2
projecting a future in shared care
designing for shared care

Having validated initial hunches and gained deeper insight into the landscape of the health outcome domains multiple directions for further inquiry emerged from the first stage of research. Instead of directly jumping into the solutioning phase the theses used design as a research tool to project future scenarios of complimentary health seeking behaviours that are social as a mechanism of discerning the future roles of designers and stakeholders.

shift from the ‘me’ to the ‘we’ paradigm

The role of design in enabling Shared Care is by creating conditions for transition to occur from the ‘me’ to the ‘we’ paradigm. This transition will occur over a period of time. For any new kind of paradigm and innovation to instill and be implemented there needs to be gradual setting up of scenarios where new interactions and thinking can thrive. The role design can play in its manifestation is through the design of products, services and systems that facilitate behaviour change and new thinking around ones health.

‘we’ paradigm

The ‘we’ paradigm is the shift from the existing accepted norm that ‘your health is your problem’. The ‘we’ paradigm is a change in approaching everyday living and systems that we interact with to consider social health and avenues of instrumentalising the re-imaging of existing norms and practices around community involvement and investment in ones life. Instead of equation health to individual motivation and expert care the ‘we’ paradigm is based on a circular value flow of support towards the people in ones immediate environment. Through rich narratives of user archetypes can the ‘we’ paradigm be better illustrated and its context validated.

Phases of transition

For any kind of behaviour change or transition in practice to occur there needs to be an initial hunch or vision of a projected future. The following transition model from the ‘me’ to the ‘we’ paradigm was created from the combined anecdotes from interviews, literature and existing services that were successful in bringing about small scale behaviour change over time. These phases will act as a guideline in creating rich narratives of applications of Shared Care and it’s adoption by different user archetypes.
The insights from the exploratory research helped crystallise archetypes of users within the transitional millennial group that would adopt Shared Care practices to embrace long-term commitment towards their health from an earlier stage in life. The stages of transition would depend on whether they need, re-build, discover or share Shared Care.

**Process**

By developing rich narratives specific to each archetype we were able to realise the potential and scope of what the intersection of social health practices would entail. Key considerations were geographic proximity, unrelated connections, informal non-expert-care and investment in place.

**Concept direction**

The scenarios were deliberate attempts to balance the sociality of health along the preventive care spectrum. Focusing on lowering barriers within existing infrastructure and behaviours that consider building stronger ties through sharing between micro-communities.
The entrepreneur transforms the style of a disclosive space by reconfiguring its practices. He or she does this by producing a new product, service, or practice which people will find themselves inclined to use. The virtuous citizen cross-appropriates practices by means of his or her speaking. And the culture figure articulates important practices which we are ignoring.


disclosive design space – experiments

Any entrepreneurial activity according to Spinosa, Flores and Dreyfus is the process of holding onto an anomaly and through the design of products, services and systems disclosing the anomaly to the world. It is in the act of realising a product, service or a system the anomaly actualises and comprehensible by the world. Anomalies by their definition usually hunches of a projected future that would not necessarily be acceptable norms of the present. Hence, it is through the courage of an entrepreneur to bring to life to an anomaly that true innovation occurs.

In order to realise Shared Care, rich narratives of future scenarios were designed. The user archetypes were used to ground the design scenarios around probable used cases of Shared Care services. A few of the scenarios were taken a step further and detailed out as working experiments of what the look and feel of these services would be like. What would the context of use be? The detailing of concepts was also an experiment in using the design process as an evaluative method to raise research questions. Instead of directly jumping into AB testing and user research this exercise was used as a mechanism to frame narrower research problems that then could be explored further. Hence, the design experiments were only seen as an initial research probe in identifying more specific tracts of inquiry.

Kin - Healthline

A community run non-profit organization that is funded by the local municipality and care centers. It is helpline run by the people of community who give support and care in the case of small time emergencies that don't always require being rushed to the hospital.

Kate's roommate recently moved out of her apartment so now she realizes she needs to build Shared Care. She begins by educating herself about Healthline and then slowly transitioning toward adopting it.

Needs addressed

Healthline addresses the need for early adopters of Shared Care who are testing the waters and not necessarily ready to be completely involved in terms of participation. By beginning to first only access information and seeking help it hopes to build trust over time with the community that is supporting the service.

Deliverable

Healthline is a phone service but it would also have a digital app component on the phone which the members of the community could use to send out text messages, access information and data about the health of the community and neighborhood.

Transition Stage

Kate finds that care pack had some really basic essentials like a digital thermometer and important contact information and helpful brochures of resources she might need in the next few days of recovery. She also tuned in to this radio show in the evening and was able to get a better sense of what was happening in her community but also learn about all the things out there for her to explore.
I was wondering if there was a flu going around? I’ve had a cough for 2 days?

Hey! I’m Kate from shadyside. Looks like there have been 2 or 3 reported flu cases from residents.

Andrew has been living in shadyside for only two months. He recently heard about kin-line a service that helps connect community members with each other for health-related concerns.

Kate has been a volunteer with kin-line for almost a year. She works 3 hours a week to help her community with information and resources that might help them with their health.

How might we enable complimentary services that provide information, support, and care towards preventive health supported by the collaboration between non-expert community members?
Kin - Apartment dashboard

kin in a software platform for apartment dwellers to manage, share and maintain their everyday routine within a closed network of individuals living in the same apartment.

Transition Stage

Jeremy just moved to a new city and is looking to rebuild his Shared Care by reaching out to potential social network in his proximity.

Needs addressed

He is new to the city and needs to learn about his neighborhood and people he could build connections with who could potentially be his support system. For simple everyday tasks one can reach out to their neighbors and community to share experiences and interests.

Deliverable

The dashboard is a platform restricted within the proximity of apartment dwellers to connect and build closed ties of support and trust to carry out everyday routines. It is manifested in the form of a physical screen in the vicinity of the apartment and is tied to a digital component that is cross platform to access information exchange.

Jeremy recently moved to Pleasanthill to be with his new friend. They just moved into their new apartment.

Jeremy discovered the apartments digital bulletin board at the entrance of the building. He was pleasantly surprised to find really interesting and useful information on it. He also found that his contact was already shared in the system.

Jeremy explores it further to find that it had some really helpful listings and resources including setting up time slots of laundry, parking maps and other amenities usage information; it also had listings of other neighborhood resources like grocery stores, hospitals and important numbers to call.

He discovers there is also a section where people to sign up for carpools.

Since Jeremy just moved to the city and he didn’t have a car he was looking for alternative modes of transport in the initial days. He sees that someone is heading out to a garage sale in the same neighborhood in a couple of hours.

He decides to request if he could get a ride and take the look at the sale.

Jeremy meets Tim who offered the carpools to the garage sale. Tim is offered to help Jeremy in any other kind of help he would need since he is new in the neighborhood for almost 3 years.

Jeremy was really happy with his decision to live in the apartment and its sophisticated information board that immediately helped him build connections with his neighbors.
how might we enable social engagement and sharing of everyday routines and wellbeing within closed apartment networks of weak tied individuals?
Kin - Apartment dashboard

kin is a community driven service that aims to bring people together through shared care. It is a place based digital platform that enables inhabitants of the same neighborhood to build relationships based on sharing resources, time and discoveries.

Transition Stage
Jeremy just moved to a new city and is looking to rebuild his Shared Care by reaching out to potential social network in his proximity.

Needs addressed
He is new to the city and needs to learn about his neighborhood and the people he could build connections with who could potentially be his support system. For simple everyday tasks one can reach out to their neighbors and community to share experiences and interests.

Deliverable
A cross platform service that enables neighbors to share and look for information relevant to their specific neighborhood. A micro-community based sharing platform.

The mobile app allows for quick updates and feedback based on location to reach out for everyday routines.

Jeremy recently moved to Pleasantville to be with his girlfriend. They just moved into their new apartment. He has been coping with one of his neighbor’s. He has been having fun for ways to engage in his hobbies like yoga and climbing but hasn’t really found a reliable source.

Jeremy decides to try kin, kin is a service that shows you community based feed of locals and visitors who engage in activities and interests specific to the neighborhood. It even shows active members of the community who are willing to mentor/ help people transition into a new place by developing new hobbies.

Jeremy sees that there is a yoga class in his neighborhood and decides to give it a try. When he sees the option of signing up with a buddy he thinks why not? It would also be a good way of getting a localized impression of what works and won’t and will help him with the awkwardness of not knowing anyone.

Jeremy meets Jane his assigned buddy for the class. She comes to pick him up and they both walk to the studio whilst talking about other fun activities to engage in the neighborhood.

Jeremy needs to reach out to potential shared network in his proximity.
how might we enable informal sharing in communities that would help them build relationships of support, trust and care?
Hi! I was wondering what kind of soup you were serving today? And how I could sign up for some?

Umm! Let’s see what I have that they could use maybe tomorrow?

Ummm! SOUP :)

Hi Kate! Hope you feel better. Thanks for the peas, we can sure think of something to make maybe tomorrow. Thank you! so much. Hope I can volunteer too next week once I’m better.
Sniff! sniff. I hope it’s not something serious.

I’m glad this made me think of all these other aspects of my health!

Hmm.. I never thought of these criterias before!

I really should have considered all these factors. I should get introduced to some of Karen’s friends.

Peer care insurance
A new kind of insurance plan that helps you identify and prioritize your health through a series of checklists and criteria that help identify the current health condition based on which you can choose which plan to pick. The healthier you are, the less you pay.

Group consultation
Shared consultations with care givers and doctors for those coping with the same stage of recovery/illness. One can choose to either meet individually or as a group but the doctor often sends recommendations depending on stages on consultation.
**Key Findings**

The key findings from the design exercise was the understanding that in order to enable transition to SharedCare practices there are two factors that are key in the adoption of any kind of behaviour change.

**Infrastructure**

With any new entrepreneurial endeavor to material there needs to be the relevant contextual tools and infrastructure that afford seamless integration into one’s everyday routines with minimal cognitive load. As in the case of creating the right conditions for people to begin to approach SharedCare as an acceptable practice there needs to be enabling and relieving physical and social agency that affords individual and collective participation. Technology and tools today are at the perfect juncture to facilitate sharing, it is a matter of finding optimal combinations of engagement that is focused towards the intersection of health and social.

**Motivation**

Motivation is key for any kind of health-seeking behaviour change to occur. Especially in the case of empowering people to share their health with a community that they would never consider interacting with. The key trigger for motivation in this case would be to design services that affords them to choose to engage on a supportive or participatory level based on effort, incentive and reciprocity. Once these boundaries are established it is easier to begin dialogue around the extent of involvement. Motivation is key even within individual health seeking behaviours and once they are able to cross over to the participatory side to sharing support it will be easier to maintain their motivation by experiencing favourable results in their own wellbeing.
Based on the key insights from the design exercise the research proposes a new framework to analyse and understand Shared Care practices. At the core of it’s application is the ‘we’ paradigm. It draws from the common focal point of the self care framework where motivation is key to any health seeking behaviour but in this case the contrasting coordinate of infrastructure considers enabling technologies and tools that are already in existence that could act as the means for transition to new health seeking behaviours that are social and invested in community.

By framing the problem space as one in which the foundation of any kind of motivation is supportive leading to the optimal that would be participatory involvement it opens up challenges to designers to ensure engagement that fits the minimal criteria without it falling back on the existing individual centric practices. Similarly, it proposes to push the involvement of infrastructure that could span across the everyday domains to consider individual and collective scenarios. This leads to considering opportunities where designers can begin to think of creative ways of contextually situating technology and existing practices around health seeking behaviors that are pro social and now exploits new realms of application.
By mapping the design experiments on the proposed framework it establishes the diverse potential to consider and approach informal health from a service design paradigm. In this case the services are supported and maintained to a great extent by the citizens of the community itself. What is key to note is that each of these potential applications of Shared Care are actually deeply situated in everyday infrastructure and activities of individuals. Housing, working, mobility, food systems and social to name a few. By explicitly identifying the specific area of intervention design can now enable more focused inquiry within each domain.

The framework also establishes a critical approach for designers to consider whilst investing in entrepreneurial endeavors in creating products and services to ensure limitations and parameters of technology. As mentioned at the beginning of the thesis ensuring pro social non tech-no centric solutions to the impending health concerns of the west should be the prerogative of creative practitioners and policy makers of today as they project a future in Shared Care. By thinking in a way of contextually mapping the present systems and finding complementary ways to frame existing problems can we really begin to innovate for a future that is rooted in solidarity.
conclusion
The future direction of a research of this kind is to unfold potentially rich spaces for further inquiry through design. By establishing new paradigms of practice and behaviour change to transition to it questions existing norms. Shared Care is a practice that has been prevalent in many cultures across the world over centuries. The mediums and infrastructure for its implementation may have been different but social support through communities and informal care systems is not a new norm discovered. However, with change in values and dynamics of the economy governing much of the philosophy shaping health seeking behaviours in the US, there was a need to critically examine and question why?

The future of Shared Care is in its cross disciplinary understanding and implementation across the diverse sectors closely tied to informal health. The framework developed to understand the current systems as well as the projected future can be used to gather foundational understanding of the significance of the way behaviours are shaped around health. The key stakeholders who will need to collaborate would be designers, architects, policy makers, non-profit organisations, technology companies, product retailers and the healthcare system to name a few. It is role of designers to now create conditions of dialogue and collaboration in order to mobilise the application of the Shared Care paradigm.
Building, discovering and maintaining new dimensions of care giving and receiving in every day activities that enable efficient breakdowns of chores through collective effort. eg. Community laundry, sharing amenities and cutting costs.

Alternate living solutions that afford and enable well rounded opportunities for people to consider environmental wellbeing as their prime priority. eg. shared space for group activities, community gardens, free group exercise activities via neighbors.

Community managed services that are low scale and organic digital platforms as management tools to enable over time use and maintenance of shared services within neighborhoods and apartment buildings.

Considering both professional ownership of specific expertise as well as developing and sharing broader and undisclosed practices that could lead to innovative combination use cases with respect to public transportation and alternative sustainable solutions.

By engaging and involving members of systems that support and lead to efficient community practices that lead to long term investment in building community. Eg. sharing skills and expertise in growing and preparing the community's food. Creating and reusing the community’s food.

By allowing flexibility in building routines focussed around individuals as well as group health dynamics that can afford sharing information, practices and support across group activities, community gardens, free group exercise activities in neighborhoods.

Collaborative ventures with local governing bodies for transportation to afford alternative mobility. Realigning and making connections within communities by shared resources of names and information, eg. the benefits focusing public transport. Impetus for the community to engage in locally grown food and maintaining healthy practices. Coupling space and infrastructure with local assets to grow awareness around healthy food habits and behavior change.

Powerful social food systems that support and nurture healthy practices leads to long term investment in building community. Sharing skills and expertise in emerging domains of sustainable micro-community building.

Adapt, build and connect with people with similar interests and contribute to growing population of people moving. By investing in a place and community an individual becomes involved in building trust across cultural diversity.

Social platforms that enable sharing information and data for long term learning and understanding place based health needs and the effect of physical and social environments.

Opportunities to consider new paradigms of service design in the realm of informal health practices that are micro-community centered and place based between individuals with weak ties as an alternative long term approach to complimentary medicine along the spectrum of preventative care.
“By 2000, it was estimated that Americans who use alternative health care spend about $500 out of pocket annually. The market for nutritional supplements was estimated at between $92 billion and $200 billion. Small wonder that 70 per cent of consumers told pollsters that availability of alternative care was a top criterion in their choice health plan.”

(Zuboff S, 2003)
The world is tired of grand solutions. It is tired of people that know exactly what has to be done. It is fed up with people walking around with a briefcase full of solutions looking for the problems that fit those solutions. I strongly believe that we should start respecting the capacity of reflection and the power of silence a bit more.

This world probably requires something extremely simple—to be together with it, and enjoy the magnificent diversity such an effort can bring about. But when I say be, I mean be, not be this or be that. This is in my opinion the greatest personal challenge each of us is faced with to be brave enough to be.

How many of us actually understand the problems we are trying to solve? Problem solving belongs to the realm of knowledge and requires fragmented thinking. In the realm of understanding problem posing and problem solving do not make sense, because we must deal with transformations that start with and within ourselves.


The journey of this thesis has unfolded as an anomaly in itself. As a design student one is expected to find solutions to wicked problems through human centered design approaches and make the world a better place. But, from the beginning what was certain about the output of this research was that there is going to be no absolute solution to a really convoluted wicked problem. Coming from a really contrasting value system and geographic setting, the US and its value system has always been a thought provoking encounter, reflecting on what is coming for the millions trying to catch up. It is not enough to fix what is wrong today and provide solutions that will be obsolete by the time all the stakeholders align their interests. The role of designers today is to be critically examining the past, the present and posing the right questions for the future. The questions could be products and services that become the interface for dialogue, but the intention of designing today has to be seen as a practice of fierce adaptability and questioning in what it creates and gives to the world.
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