

## Caring Communities

Today's on-going demographic change presents modern societies with one of the biggest and most complex global challenges. As demographic evidence shows, our life expectancy has continuously risen over the past 160 years and in today's ageing societies an increasing proportion of the elderly population need care and medical assistance.<sup>1</sup> While the dramatic improvement of health standards in industrialised societies throughout the past centuries was primarily a result of public health measures, it is biomedicine which is making significant strides in developing treatments and medications to address age-related health issues - at times effectively, at times with bitter side effects.<sup>2</sup> It seems paramount, however, to likewise incorporate the social and cultural aspects of the unprecedented and unparalleled proliferation of chronic ailments.

This paper attempts to increase our understanding of communities and how they may foster a healthy and particularly caring environment. In doing so, it will shed light on broader issues in the study of human ageing and cohabitation. Can we learn from cultures that seem to age 'successfully'? Can we merge their healthy lifestyles with our Western and highly medicalised care systems? Above all, how do successful communities work and how can they last? These questions speak to a set of further considerations that ought to be placed in a much broader context of public health and medical history. The changes in the socio-medical landscapes we are witnessing in today's modern societies urge us to examine the role of community care in relation to health. This article further aims to explore the relationship between community and care and how these concepts heavily depend on the socio-political and cultural-moral context. I begin with examples of communities in which cohabitation arrangements have an astonishingly positive influence on their members' health. This is followed by a discussion of the key factors which appear to contribute to a community's resilience and vitality and I address research which suggests that social support and a caring environment may even decelerate the biological ageing process. In contrast, I will then consider how the shift from institutionalised medicine and care to more community and home-based approaches are in conflict with the social realities of those facing chronic and age-related diseases and how the split between the two seems unbridgeable.

I build my arguments on the foundation of medical historical research which has attended to the trends toward institutionalised medicine, the demographic transition, and the causes and outcomes of the rise of chronic disease. Mirko Dražen Grmek, for instance, raised important and on-going questions in the intersection of society and health, by emphasising the significance of society's environmental and cultural

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<sup>1</sup> Jim Oeppen and James W Vaupel, 'Broken limits of life expectancy', *Science*, 296 (2002), 1029-1031.

<sup>2</sup> Roy Porter, *The Greatest Benefit to Mankind: A Medical History of Humanity* (London: Harper Collins, 1997), pp. 84-85, 136-38.

factors and reminding us that no disease should be examined without including all other diseases in the relevant society. His theory of *pathocenosis* is just as resonant today.<sup>3</sup> In his outstanding chronicle ‘Allergy: the history of a modern malady’, Mark Jackson depicts, as Anne-Marie Moulin succinctly put it, ‘the elusive nature of medical truths, the volatile character of classifications, and the controversial character of tests’ which are attached to modern maladies and how they are thoroughly embedded in our social and cultural systems.<sup>4 5</sup> Thomas McKeown’s historical analysis, on the other hand, in which he ascribed the modern world’s population growth to wide-ranging social and economic changes as opposed to targeted medical interventions or public health measures, has a continuing resonance today, even though scholars have called for and offered more nuanced and comprehensive views.<sup>6 7 8</sup> Placed within this relevant critical context, this paper ultimately seeks to provide a useful discussion of communities and how they can foster well-being and care.

### *The Roseto Effect: The Power of Clan*

In his bestselling book ‘Outliers’, Canadian journalist and author Malcolm Gladwell recounts the intriguing story of the people of Roseto, a small town in Eastern Pennsylvania, which caused a great stir among scientists in the late 1960s.<sup>9</sup> Populated by immigrants from a village in Southern Italy, the community appeared to be an ordinary provincial settlement. The men worked strenuous jobs in neighbouring slate quarries. They smoked tobacco and consumed their obligatory few glasses of wine in their leisure time. Rosetan residents kept to a traditional Italian diet that had been moderately Americanised with local ingredients. In brief, nothing about local conditions of living foreshadowed the considerable public and scientific attention which the town received. The excitement began when a Rosetan physician shared a bewildering observation with colleagues at an American Medical Association conference. Though having practised medicine in and around Roseto for more than seventeen years, he had never had a single Rosetan resident under the age of sixty-five suffer from a heart attack. At the time, heart attacks presented one of the country’s most common causes of death. In fact, the townspeople of Roseto showed only half of the cardiac incidences found in the rest of the American population. Mystified by this second-hand information, medical researchers and sociologists flocked to the town, determined to uncover the magic ingredient thought to render the residents immune to the nation’s most common killer.

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<sup>3</sup> Mirko Dražen Grmek, *History of AIDS: Emergence and Origin of a Modern Pandemic* (Woodstock, Princeton University Press, 1990), pp. 279.

<sup>4</sup> Mark Jackson, *Allergy: the history of a modern malady* (London: Reaktion Books, 2006), pp. 288.

<sup>5</sup> Anne-Marie Moulin, ‘Book Review, Allergy: the history of a modern malady’, *Medical History*, 51 (2007), 404–406.

<sup>6</sup> Thomas McKeown, *The Modern Rise of Population* (New York: Academic Press; 1976), pp. 168.

<sup>7</sup> Edward Anthony Wrigley and Roger Schofield, *The Population History of England 1541–1871: A Reconstruction* (Cambridge: Cambridge University Press; 1981), pp. 779.

<sup>8</sup> Simon Szreter, ‘The importance of social intervention in Britain’s mortality decline c. 1850-1914: a reinterpretation of the role of public health’, *Social History of Medicine*, 1 (1988), 1-38.

<sup>9</sup> Malcolm Gladwell, *Outliers: The Story of Success* (London: Penguin Books, 2008), p.9.

Their discovery was startling. Whereas the Rosetans' diets were not particularly healthy and the majority of adults were in fact overweight, life did seem to be more peaceful: no suicides, no drug addictions, no crimes, and no gastric ulcers plagued the town. This led the researchers to believe that there had to be something unique about the Rosetan lifestyle that caused their serenity and coronary superpowers. And indeed, what set the people in Roseto apart from other communities was the communal way in which they how they organised and structured their communal lives. In Roseto, up to three generations frequently lived under one roof. The residents engaged in various social clubs and it was common to speak to other residents in the streets. Dinner was a social affair with families and friends gathering to share gossip, news and jokes, and the church organised festivals where the community celebrated in unity. It was precisely these particular forms of cohabitation and community that appeared to be the origin of the Rosetans' vital energy and resistance to age-limiting coronary diseases. It was a healthy mix of cooperation and mutual respect which was determined to play a significant role in the inhabitants' health and welfare – what is known today as the 'The Roseto Effect'.<sup>10</sup>

These observations were summarised in 'The Power of Clan - The Influence of Human Relationships on Heart Disease', a revised report on the observations of the physician Stewart Wolf and sociologist John Bruhn who had both investigated the Rosetons' communal rituals over an extensive period of time. They concluded that in Roseto they had encountered a culture which

'radiated a kind of joyous team spirit as its inhabitants celebrated religious festivals and family landmarks such as birthdays, graduations, and engagements. Their social focus was on the family, whereas neighbouring communities, holding to the traditional American view, were more likely to focus on the individual as a unit of society'.<sup>11</sup>

This was more than forty years ago, and the Roseto effect has since been discussed and digested in a number of articles and books. The town of Roseto itself, however, did not sustain its exceptional health statistic. The townspeople worked long and hard hours to offer their children a good education. With education came material wealth and a desire to lead a life that fit the white American individualistic standard, with single family houses, country clubs, and more freedom from the traditional, and sometimes rigid, communal lifestyle. As these changes occurred, the community's health status, slightly but noticeably, started to deteriorate. The Rosetons' heart attack rates gradually aligned themselves with the national average.<sup>12</sup>

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<sup>10</sup> Brenda Egolf, Judith Lasker, Stewart Wolf and Louise Potvin, L, 'The Roseto effect: a 50-year comparison of mortality rates', *American Journal of Public Health*, 8 (1992), 1089-92.

<sup>11</sup> Stewart Wolf and John G Bruhn, *The Power of Clan: The Influence of Human Relationships on Heart Disease* (New Brunswick: Transaction Publishers, 1993), p.10.

<sup>12</sup> The authors summarised their results as follows, 'Rosetans had a lower mortality rate from myocardial infarction over the course of the first 30 years, but it rose to the level of Bangor's [the control group] following a period of erosion of traditionally cohesive family and community relationships' Egolf, *The Roseto effect*, p. 1089.

*The Blue Zones': Lessons for living longer*

Interested in the salient questions of longevity, a group of Belgian and Italian researchers recently examined the gerontological characteristics of the people living on the Italian island of Sardinia.<sup>13</sup> What they found set in motion a chain of follow up research dedicated to unlocking the Sardinian's secret to longevity. The researchers had discovered that an astoundingly high proportion of healthy elderly men lived in a narrow sub-region of the island. They argued that what set the men apart from their mainland countrymen and women, was not their genetics but their lifestyle. Almost all of the men worked as shepherds and spent their days in open air, with plenty of natural exercise, sunshine, and a balanced Mediterranean diet.<sup>14</sup> Inspired by those findings, and at the behest of the National Geographic magazine, journalist Dan Buettner set out to undertake an extensive fieldwork project to detect and define what became known as the 'Blue Zones', geographic regions and sub regions where people lived a considerably healthier and longer life compared with the average demographic.<sup>15</sup> Specifically, he found elderly populations in Loma Linda, California, the Okinawa Islands in Japan, the Nicoya Peninsula in Costa Rica, and on the Greek Island of Icaria. Despite their geographical, ethnic, and cultural differences, they shared one common trait: their ability to grow old without the complications of severely debilitating illnesses, be they of a physical or mental nature.

In line with the observations from Sardinia, it appeared that it was mainly a particular set of lifestyles which was causing the study subjects' healthy longevity rather than a reliance on Western medicine's pharmaceutical solutions or a particularly resilient genetic disposition. By comparing the lifestyles of the different populations, Buettner discovered a remarkable set of similarities in how they went about their daily lives. First, they all showed a strong sense of family brought about with the observance of rituals and traditions. Second, they ate a predominantly vegetarian diet, heavy in fruits and vegetables, and consequently low in calories. Moreover, they exercised restraint in the consumption of both alcohol and tobacco. Third, all groups felt a deep sense of life purpose, or, in Buettner's words, a strong idea of 'why I wake up in the morning'. Okinawans would refer to this as 'ikigai' while Nicoyans would name it 'plan de vida'. Fourth, the members of the community led an active lifestyle. While going about their daily chores they moved naturally. In other words, they incorporated movement into their daily lives rather than adhering to a strict exercise routine. Fifth, they all formed part of a spiritual community providing a safe

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<sup>13</sup> Michel Poulain, Giovanni Mario Pes, *et al.*, 'Identification of a geographic area characteristic by extreme longevity in the Sardinia island: the AKEA study', *Experimental Gerontology*, 39 (2004), 1423-1429.

<sup>14</sup> Michel Poulain Giovanni Mario Pes, and Luisa Salaris, 'A population where men live as long as women: Villagrande Strisaili, Sardinia', *Journal of Aging Research*, 2011 (2011), <http://dx.doi.org/10.4061/2011/153756>.

<sup>15</sup> Dan Buettner, *Blue Zones. Lessons for living longer from the people who've lived the longest*, (Washington: National Geographic, 2008), p. vii.

and nurturing environment for its members. Finally the individual's membership and participation in a tight-knit social network both protected and supported them. The findings surrounding the Roseto effect and the Blue Zone study provoke the question whether such systems provide appropriate institutional as well as personal solutions for the diverse difficulties today's ageing societies face. Indeed, for many centuries if not millennia, philosophers, historians, and researchers from multiple disciplines have been interested in the simple yet profound question of how to live a long, prosperous and healthy life.

Encouraged by Buettner's findings, some communes in the United States have been trying to adopt the Blue Zone characteristics.<sup>16</sup> Meanwhile, various public policies have made attempts to create environments which foster healthy ageing. In elderly care in particular, the community aspects increasingly take centre stage, as seen with the heightened media attention and public interest in the dementia village projects in the Netherlands and Germany.<sup>17 18 19</sup> Other comparable projects might be multi-generational homes, a form of cohabitation which has been gaining popularity in Germany.<sup>20</sup> Whereas such homes were the norm for most previous generations, they now have become primarily a policy tool to provide a more economical alternative to costly nursing homes. Yet, it seems that ventures of that sort, which are not historically rooted and have not evolved organically but were conceived in a deliberate and artificial fashion, are susceptible to a multitude of problems.

Returning to the examples above, we can readily see that certain communities do indeed provide a particularly enriching social environment. What sets Roseto and the Blue Zones apart from artificially created societies, however, is their investment and deep-rootedness in their population's culture. Culture is as much part of our lives as genes are part of our body. Both create, shape, and mould us, influence the way we think, act, and react. As such, our heritage and upbringing is of great consequence and we learn our beliefs and appropriate conduct from our immediate family and friends, from groups with whom we associate ourselves. Culture is interrelated and there is a strong correlation among all factors which not only define our personal lifestyles and health behaviour but also a significant part of our living and working conditions. If the Blue Zones truly do hold the magic secret to a healthy long life, how these communities are built and how they interact and communicate might just be as important as their diet and exercise routines. Most critical though is the question of sustainability. What keeps such communities alive? Why do some succeed, while others fail? And what makes it so difficult to bring cohabitation projects to fruition?

### *The Creation of Prosperous Communities*

<sup>16</sup> Dan Buettner, 'The vitality city makeover', in Easy Reader <<http://www.easyreadernews.com/32217/vitality-city-makeover/>> [accessed 29 April 2015]; Dan Buettner, 'Gaining vitality: how the "Blue Zones Makeover" changed lives', in Easy Reader <<http://www.easyreadernews.com/50292/blue-zone-dan-buettner/>> [accessed 29 April 2015]

<sup>17</sup> Dan Hurley, 'Village of the Demented' Draws Praise as New Care Model', *Neurology Today* 12 (2012), 12-13.

<sup>18</sup> Lisa Berry, 'Lessons from abroad', *Nursing Older People* 25 (2013), 3.

<sup>19</sup> Catharine Jenkins and Analisa Smythe 'Reflections on a visit to a dementia care village', *Nursing Older People*. 25 (2013), 14-19.

<sup>20</sup> Frank Eckardt, 'Das deutsche „Mehrgenerationenhaus“: Die falsche Antwort auf ein komplexes Problem', *Sozial Extra* 30 (2006), 32-36.

In her 1972 book, Rosabeth Moss Kanter carried out an extensive analysis of the nature and processes of enduring commitment in communes, grounding her theory on comprehensive research of nineteenth-century utopias and a variety of contemporary groups.<sup>21</sup> The book came out at a time of a renewed pursuit for utopian communities, when especially America experienced a rather brief heyday for communes and alternative, group-oriented ways of cohabitation. Kanter's insights can shed light on some of the challenges many of today's intentional communities and experimental living arrangements encounter. Historically, communes have predominantly grown out of critiques of society, grounded in religious zeal, politico-economic weariness, or psychosocial conviction. Yet, regardless their motivation, almost all showed a moderately poor record of longevity.<sup>22</sup>

According to Kanter, several utopian ideas fostered the creation of prosperous communities. First, it is the notion of human perfectibility, seen in the belief that friction, discord and disagreement originate from the social conditions that are shaped and controlled by the environment. They do not stem from within the individuals forming the community. Consequently, it is not the society's members who are the source of human difficulties but rather the societies themselves, in their structural and cultural totality, which have corrupted their members. In essence, human beings are inherently good and have an infinite capacity to lead a happy and peaceful existence.<sup>23</sup> Second, a thriving community needs order to not only provide stability but also sense of purpose. The members dissociate themselves from society at large, in which life is disorganised, frenzied, and messy, thus leading to inadvertent, haphazard, and often meaningless events. Through deliberate organisation and harmonisation and by aligning all community events and gatherings with the group's values and principles, each member's wellbeing is enhanced. In this manner, the members can fill their lives with meaning and direction.<sup>24</sup> Third, the community is held together by personhood, which speaks to people's inner most nature, namely their desire to unite with others. This bond of alliance is sealed with the promise of respect for humanity and demonstrates how men can live in harmony just as harmony is achieved between the social world and nature's universal laws.<sup>25</sup> A fourth value concerns the relationship between body and spirit, or body and mind, and seeks to understand the two as distinct but interacting entities. Taking this fundamentally Aristotelian position, a unity of body and mind is seen as a further important contributor to harmony.<sup>26</sup> Fifth, utopian communities distinguish themselves by virtue of their relatively high level of experimentation. They not

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<sup>21</sup> Rosabeth Moss Kanter, *Commitment and Community - Communes and Utopias in Sociological Perspective* (London: Harvard University Press, 1972), pp. 1-66.

<sup>22</sup> There are, of course, communal groups such as the Kibbutz (Israel), the Shakers (US) and Oneida (US) who unlike the unsuccessful 19th-century American communities Kanter studied persisted at least 25 years. These are all religious social-movement organisations (see Benjamin David Zablocki. *The Joyful Community: An Account of the Bruderhof: A Communal Movement Now in Its Third Generation* (Chicago: University of Chicago Press, 1971). pp. 1-362. or Keith Melville, *Communes in the counter culture: origins, theories, styles of life* (New York: William Morrow and Company, 1972), pp. 1-256.)

<sup>23</sup> Rosabeth Moss Kanter, *Commitment and Community - Communes and Utopias in Sociological Perspective* (London: Harvard University Press, 1972), p. 33.

<sup>24</sup> *Ibid.*, p. 39.

<sup>25</sup> *Ibid.*, p. 43.

<sup>26</sup> *Ibid.*, p. 49.

only explore novel forms of relationships but also show a high willingness to try new approaches within the community itself.<sup>27</sup> Lastly, the community generally displays a high level of coherence. Its members are very conscious of their unique role in history and are extremely aware of their boundaries — whether physical or symbolic in nature. Membership can be clearly defined through established requirements and distinct entrance procedures. They know who belong to the group and who does not, where their land begins and where it ends. The outside world can be clearly distinguished, what is inside is part of the utopian world, what is outside is not.<sup>28</sup>

While these values all present supporting pillars of utopian communities, it is various forms of commitments which act as their cornerstones according to Kanter. A profound desire for social unity lies at the heart of those communities. Membership is voluntary and based on shared values. Given that one is free to choose to join and stay, the survival of a social group depends on the degree of its members' participation and, in particular, their levels of commitment to the group's ideals and unity. Enduring group movements know how to motivate their members to devote time, energy, money, and other resources to their group. When Kanter turned her attention to why some communes prevailed longer than others, she found that besides a distinct ideological separation between the community itself and the wider society, establishing affirmative social norms, which prioritise commitment over coercion, is a key factor.

‘Utopia is held together by commitment rather than coercion’, she states, ‘for in utopia what people want to do is the same as what they have to do; the interests of the individuals are congruent with the interests of the group; and personal growth and freedom entail responsibility for others’.<sup>29</sup>

Such forms of commitment or in Kanter's words the ‘attachment of the self to the requirements of social relations that are seen as self-expressive’ arguably not only determine the successful development of a communal venture but also its longevity.<sup>30</sup> She then differentiates between three modes of personal orientation: the instrumental, the affective, and the moral, which all connect the individual to the social system to various degrees. This crucial connection is sustained through several commitment mechanisms. On an instrumental level, attachment to the community is achieved through investments and sacrifice. Often this requires an irreversible investment and the member's inability to neither reclaim their initial investment nor receive compensation for their work in case they left the community. On an affective level, commitment entails renunciation and communion, as seen in the abstinence from sex, food, or drink, or generally austere and frugal lifestyle. Morally, members are tied to the group by acts of mortification, which seek to eradicate the members' former identities and turn the community into their primary source of identification. This can happen through confessions and practices of mutual criticism, which foster the

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<sup>27</sup> Ibid., p. 51.

<sup>28</sup> Ibid., pp. 52-53.

<sup>29</sup> Ibid., p. 1.

<sup>30</sup> Ibid., p. 66.

needed deindividuation and helps members differentiate themselves both spiritually and emotionally from outsiders. The communities Kanter examined did not make use of all these mechanisms at once and various forms of commitment were found in different models. Those communes, however, which survived for longer than twenty-five years and as such could be deemed successful in their mission to form long-lasting human relationships, were much more likely to deploy some of the aforementioned commitment practices.

### *The Disintegration of Communities*

Despite their relative success, the 19<sup>th</sup> century communes which formed part of Kanter's research ultimately perished. This was either due to an alienation from their original ideals, a failure to adapt to transforming environments, or simply the inability to sustain enough members. Living according to clear and concise visions and values while simultaneously dealing with the everyday trepidations of cohabitation as one cohesive group regularly proved an insurmountable task. In the course of time, ideals often had to yield to practical concerns and the idealistic basis for a communal ideological basis, was moulded and undermined. In terms of the existing and emergent communes in the late sixties and early seventies, Kanter divided the communities into two separate groups - retreat and service communes. While the former predominantly sought to offer a refuge from the overly technological and grossly materialistic society, the latter saw their role as helpers serving society and by doing so reforming it from within. Yet, in both cases and similar to the historical movements, Kanter argued that it is various contradictions inherent in communal life, and ultimately a lack of commitment, which lead to the dissolution of intentional communities. Though their members initially join the commune to break free from society's authoritarian grip and gain control over their own fate, the existence, and persistence of that new community, paradoxically, can only be sustained by establishing its own authoritative structure. It is this friction between freedom and constraint, individuality and homogeneity, which seems to plague all intentional communities and ultimately rendering them, in the long run, a utopian ideal virtually impossible to maintain.<sup>31</sup>

The longing for more inclusive, collective care models which place emphasis on human relationships and solidarity rather than calculated self-interest is found in many care circles. Meanwhile, the search for the secret of long-lasting and healthy lifestyles in the Blue-Zones and the study of the social mechanisms which contribute to a healthy and caring environment demonstrate the vested interest Western societies have in new models which are better suited to cater for the psychological, social, and medical needs of the

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<sup>31</sup> Whereas Kanter saw commitment as the bond by which group objectives and individual biographies become aligned, sociologists John Hall applied Rational choice theory to explicate how the commitment problems Kanter described are resolved in alternative cultural structures of social organisation. In communities, he argued, social cohesion is achieved via ethnicity and in other-worldly sects it is social control stemming from hierocratic domination (John Hall, 'Social Organization and Pathways of Commitment: Types of Communal Groups, Rational Choice Theory, and the Kanter Thesis', *American Sociological Review*, 53 (1988), 679-692).



elderly and chronically ill. In spite of contemporary medicine's unprecedented ability to cure many illnesses and its remarkable success in sustaining life, the difficulties and complexities in age-related chronic illness seem to have been stoked rather than soothed in the process and continue to roil an increasing part of society.

One concern which ties into this discussion regards the issue of urbanisation, an increase in population density, and the resulting forms of pathological behaviour and isolation. As we have established, interpersonal relationships influence our well-being and our general health. Living in confined, populated spaces in metropolitan areas, however, often leads to a loosening of the personal bonds and may, in particular for the elderly, bear serious consequences. Not only is social isolation associated with elevated stress hormones but also with our life expectancy. In 2013 researchers working in tandem with psychologist Andrew Steptoe of University College London examined the data of over 6000 elderly men and women taken from a longitudinal study on ageing.<sup>32</sup> Their work revealed that social isolation was an exceptionally distressing factor for the elderly, especially if they were excluded from social life due to health reasons or immobility. Another factor was whether most of their friends and companions had pre-deceased them. To detect their level of social isolation, the researchers looked at whether the individuals were married or not, how close they were with family members and friends, and how involved they were in local clubs and organisations. Reportedly, the most socially isolated individuals were more likely to die within the seven year timespan of the study. Yet, Steptoe and his colleagues were able to allay their initial suspicion. It was not perceived loneliness and a lack of social contacts which had impaired the study subjects' mental health and general welfare; it was much more the lack of social support. When social density and social isolation coincide, a toxic mix emerges. Consequently the question must be asked: do such studies truly have important implications for how we should deal with ageing?

The studies suggest that once an elderly person is without a community and ties, living in an isolated, puzzling, and unsupportive world, death will be near. Or could it be that urban, anonymous life inherently attracts mentally fragile people? The difficulty is, in part, a consequence of the problem seen in many observational surveys, whereby the data are often over-exploited to find or suggest causation. A crucial lesson frequently taught in introductory statistics class is that when two variables correlate, they are not necessarily causally related. To find causation, experimental and not observational data is required. Often, we are even presented with the possibility of reverse causality. Does social drinking, for instance, lead to higher salaries? 'No Booze, you may lose', stated Peters and Stringham in a recent publication, showing that drinkers generally earn more money than non-drinkers.<sup>33</sup> Yet it could be equally argued that people with higher salaries take to the bottle due to a greater disposable income or from the resulting stress of their high-paying jobs. Likewise, it appears that when it comes to ageing, the direct effects of any one factor are particularly difficult to unravel. While some substantial and negative impacts may be exposed,

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<sup>32</sup> Andrew Steptoe, Aparna Shankar, Panayotes Demakakos, and Jane Wardle, 'Social isolation, loneliness, and all-cause mortality in older men and women', *Proceedings of the National Academy of Sciences*, 110 (2013), 5759-5801.

<sup>33</sup> Bethany L Peters and Edward P Sandtringham, 'No Booze? You May Lose: Why Drinkers Earn More Money Than Nondrinkers', *Journal of Labor Research*, 27 (2006), 411-21.

definite answers and determinants should be met with suspicion, as many studies tend to neglect the complexities in devising the required trials on which most claims are based. The data are often messy, random, unrepresentative, or incomplete. In particular, no experiment or investigation can ever last long enough to determine the essential links between life and death, or life and an age-limiting disease. Though some studies are very helpful in understanding ageing better, the richness and diversity of the various factors involved require much consideration and care.

### *Reversed Ageing in Communities*

In the late 1970's an experiential study with a short timespan but bearing seemingly important implications aroused the attention of psychologists. The study shed light on other aspects of community life and supports the notion that fundamental difference exists between chronological and biological age. In fact, it suggested that biological age is different, in that unlike chronological age, it ought to be a question of choice, power of thought, and the right environment rather than a specific number. In 1979 social psychologist Ellen Langer led an experiment with a group of elderly people in a remote monastery. The men, all in their late seventies and early eighties, were divided into two groups of eight participants each.<sup>34</sup> Both groups stayed in the monastery for a week. The first group was asked to reminisce about their lives twenty years earlier. At the same time, they had to go about their daily activities as self-sufficiently as possible. They carried their own suitcases, prepared their own meals, all without the usual amenities and safeguards commonly provided in care homes or age-appropriate housing. The second group, by contrast, virtually stepped into a time machine. They lived in a setting that was modelled after a location which would have existed in 1959. They watched black and white television, listened to music by Nat King Cole, and watched movies like *Ben Hur*. In essence, they were to pretend they were twenty years younger, talk in the present tense, and live in the past as though they had magically rejuvenated by one fifth of a century. Everything that had happened in their lives after the late 1950s was taboo to mention. Langer imagined that by doing so, she could rewire their mentalities towards a former self that was younger and more energetic. Immersed in this time capsule, making their own choices and relying on an imagined healthy constitution, they would not only feel younger but become all together younger in both physical and mental terms.

The study participants complied with Langer's parameters and the results of the experiment were remarkable. Over the course of the week, Langer started to observe obvious changes in the subject's behaviour. They began walking at a faster pace, displayed more self-confidence, and seemed to tap into energy resources they never thought they had before. Besides this anecdotal evidence, physiological changes could be measured. By the end of the study, the flexibility of the subjects' joints had increased, they scored higher on intelligence tests, and their memory improved. What is more, drop in blood

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<sup>34</sup> Ellen Langer, *Counterclockwise: Mindful Health and the Power of Possibility* (London: Hodder & Stoughton, 2010), pp. 1-240.

pressure and even improved hearing and eyesight could be evaluated. This was the case with both groups, yet while the control group, who merely reminisced about their former lives showed slight improvements, it was the experimental group which had significantly better results. When growing old it seems that our physical and mental decline is strongly influenced by our conceptions of ageing and of the images of elderly people we carry in our mind. So are we truly as young as we feel?<sup>35</sup> And above all, can we learn from cultures that seem to age ‘successfully’?

While the accounts of healthy ageing and, in this previous example, reversed ageing have and continue to capture the imagination of many scientists, the individual experience of those who age and how they feel towards their bodies, mind, and emerging health complications often paint a different picture. In reality, health is seldom the most obvious interaction with our environment. As we age, disease and sickness and not health and wellbeing are the common carrier of our identities. And as much as the above examples stress the importance of community, lifestyles, environments, and even mind-sets (and therefore should influence our notions of healthcare provision and care), our current practices are riddled with contradictions. Not only does our environment lack the levels of commitment Kanter described, but our ideas about health and ageing are also inevitably and inseparably linked to the presence or absence of disease. Meanwhile, the prospect of a cure, an absence of illness, and a reversal of ageing remain the dominant legitimising forces in our concept of care and medicine. How do chronic illnesses play into these trends? It is pathology in the individual, not wellbeing in a group, which pervades our Western conception of health and care.<sup>36</sup> Moreover, it appears that our solution to this perceived double standard is not to carve out antiquated care models, but to add new practices to existing ones.

### *The Paradox of Care*

Historically, our governing care paradigms were directed at infectious diseases, administering acute as opposed to chronic treatments. Paradoxically, the very methods which arguably had us grow to such a ripe old age now appear ill-equipped to cater for the needs of the chronic disease patients these same methods

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<sup>35</sup> Even though the study took place in 1979, Langer did not discuss her study in full detail until the publication of her book ‘Counterclockwise’, in which drawing on various other experiments, she thoroughly described the outcome of her 1979 research. ‘If a group of elderly adults could produce such dramatic changes in their lives, so too can the rest of us’, she concludes. ‘To begin, we must ask if any of the limits we perceive as real do exist. For example, we largely presume that as we age our vision gets worse, that chronic diseases can’t be reversed, and that there is something wrong with us when the external world no longer “fits” as it did when we were young. Why is it that, as a society, we pay so much attention to our health and yet we know so little about achieving a healthy life?’ Langer, *Counterclockwise*, p. 187.

<sup>36</sup> Bali (Indonesia) is a common example of where the aggregate health of the community is prioritised (see Unni Wikan, *Managing Turbulent Hearts: A Balinese Formula for Living* (London: University of Chicago Press, 1990), pp. 1-343). Though it must be noted that the Indonesian Government has implemented significant health sector reforms to designing incentives for health providers and and improve the quality of physician training and patient care according to Western models of health and pathology (see Claudia Rokx and John Giles, *New Insights Into the Provision of Health Services in Indonesia: A Health Workforce Study* (Washington: World Bank Publications, 2010). Pp. 1-139).

groomed. Moreover, taking care of chronic diseases demands care practices which are far less attractive and life-changing (or life-saving) as those designed for acute, therapeutic care.<sup>37</sup> Or, as Stuckler, *et al.*, succinctly phrased it, ‘in managing chronic disease, there are no medical heroes who save lives on the operating table’.<sup>38</sup> They further list three reasons as to why the persisting concepts of care are outdated and out-of-touch with today’s medical challenges. First, the common biomedical approach is curative, intending to freeze the advancing erosion caused by a chronic illness.<sup>39</sup> Yet, the approach to chronic illness care cannot be curative, as cures have not been devised or come with countless side effects leading to alternative illnesses. Second, a chronic disease is typically accompanied by vast complications and so-called co-morbidities, often having patients ‘ping-pong’ from one expert to another.<sup>40</sup> Preventing this would require a strong harmonisation and integration of biomedicine’s specialised fields and skills, a pressing need which also exists in curative medicine.<sup>41</sup> Third, social and environmental factors are becoming increasingly valued, which have long been considered negligible in a care environment where doctors are neither prepared nor particularly concerned with the tedious, day-to-day realities of care and the social relationships patients maintain.

These new realities have yielded new care concepts, laying their focus on holistic treatments. They include chronic disease care models,<sup>42</sup> palliative care,<sup>43</sup> community-based care,<sup>44</sup> relationship-centred care,<sup>45</sup> or person-centred care.<sup>46</sup> The models all share similar characteristics, placing emphasis on person-centred care as a core value. In the fashion of other general chronic disease models, they seek to prevent unwarranted institutionalisation, empower patients to manage and know about their medical conditions, and enable collaborative decision-making among patients and physicians.<sup>47</sup> Most Western countries have implemented such approaches and significant efforts are devoted to expand the provision for a care system which address the needs of patients with life-limiting rather life-threatening diseases.<sup>48</sup> <sup>49</sup> Indeed, care services have been significantly diversified in recent years and those requiring care and support can, in theory, now choose from a wide array of possible care provisions, ranging from inpatient care in an

<sup>37</sup> Tobias Haeusermann, ‘Careful: Do touch’, in *King’s Review*

<<http://kingsreview.co.uk/magazine/blog/2014/08/13/careful-do-touch/>> [accessed 30 April 2015]

<sup>38</sup> David Stuckler, Karien Siegel, Kathleen O’Connor Duffany, Sandeep Kishore, Denise Stevens, and Sanjay Basu, ‘Comprehensive strategies to reduce the burden of chronic diseases’, in *Sick Societies: Responding to the global challenge of chronic disease*, ed. by David Stuckler and Karen Siegel (Oxford: Oxford University Press, 2011), pp. 87-134 (p. 97).

<sup>39</sup> A strategy commonly termed ‘maintenance management’. Stuckler, *Sick Societies*, p. 94.

<sup>40</sup> *Ibid.*, p. 94.

<sup>41</sup> Atul Gawande, *The Checklist Manifesto: How To Get Things Right*. (London: Profile Books, 2010), pp. 15-48.

<sup>42</sup> Edward H. Wagner and Trish Groves, ‘Care for chronic diseases: the efficacy of coordinated and patient centred care is established, but now is the time to test its effectiveness’, *British Medical Journal*, 325 (2002), 13-14.

<sup>43</sup> Julia Addington-Hall, W. Fakhoury, W. and M. McCarthy, M, ‘Specialist palliative care in nonmalignant disease’, *Palliative Medicine* 12 (1998), 417-27.

<sup>44</sup> Stuckler, *Sick Societies*, p. 97.

<sup>45</sup> Mike Nolan, Susan Davies, S. Jayne Brown, John Keady, J, and Janet Nolan, ‘Beyond “person-centred” care: a new vision for gerontological nursing’, *International Journal of Older People Nursing*. 13 (2004), 3a (pp. 45-53).

<sup>46</sup> Tom Kitwood and Sue Benson, *The new culture of dementia care* (London: Hawker Publications, 1995), pp. 1-80.

<sup>47</sup> Stuckler, *Sick Societies*, p. 95.

<sup>48</sup> Palliative care, for instance, refers to an approach which is intended to support people until they die, rather than curing them. Developed in the U.S. in the 1960s, it primarily sought to address the needs of cancer patients, until recent diversification in the 1990s aimed to also direct the approach to other condition such as dementia. Addington-Hall, *Palliative Care*, p. 417-27.

<sup>49</sup> also see Haeusermann, *Careful: Do touch!*

institution, to a residential community to home care. North and Central-European countries, in particular, have devised a variety of innovative forms of housing such as assisted living communities, with an aim to reinforce civic engagement and to allow people to live in their familiar surroundings as long as possible. It is thus assumed that individuals want to lead self-determined and dignified lives in their habitual living environments, even if they are dependent on care, help, and support. As a result they remain part of society and the support and care services are geared not only to their medical but also psychosocial needs. Through a viable and dynamic network of care and residential services the ageing population is thus offered individual solutions, where home care, or outpatient care in professional jargon, is prioritised over inpatient, or institutional care. Hence, people live in their own four walls and embedded in their own community as long as they possibly can. Only when their care needs cannot be otherwise covered are they to move to a nursing home. There seems to be a vast gap between theory and practice, however, and the implementation of care models does not inevitably lead to better care. As Wagner and Groves note, ‘the efficacy of coordinated and patient-centred care is established, but now it is time to test its effectiveness’.<sup>50</sup>

There are many other concerns clouding the hopeful visions of patient-centred and chronic disease focused care. Chronic care is time and cost intensive. Whereas in Western countries the modern welfare states were instituted with fanfare, overall spending on chronic healthcare has skyrocketed. Despite obvious ethical red flags, dominant economic views tend to commodify health by attaching a price tag to our treatments of diseases. Meanwhile, the unavoidable question arises time and again: ‘How do we put a price on human life?’<sup>51</sup> And how do we control the rising health care bills? It seems inevitable that such concerns will gain even more importance in the future. Moreover, in current times of austerity cuts and the reconfiguring of the welfare state seen in Western-Europe, the tension between outpatient and inpatient care re-emerges in the assumption that everybody can perform care work. It should be remembered that the emphasis on an individual’s care-friendly home environment and their communal and family ties predicates on the supposition that such environments and ties truly exist and have been nurtured over time.<sup>52</sup> The ideals of kinship, trust, intimacy, support, and cohesion must be confronted with the social realities. Not only do they stand in stark juxtaposition to the notions of autonomy and independence that form a central pillar of the outpatient model, but they also need to be balanced against the professionalisation of care and medicine commonly seen in industrialised societies. The universality of home as a place for care leads us to comprehend it as both undisputed and natural and we tend to neglect or underrate the ways in which it is culturally determined. Such ideas are strengthened by

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<sup>50</sup> Wagner, *Chronic Diseases*, p. 13.

<sup>51</sup> David Stuckler and Marc Suhrcke, ‘Social and economic consequences of chronic diseases’. in *Sick Societies: Responding to the global challenge of chronic disease*, ed. by David Stuckler, and Karen Siegel (Oxford: Oxford University Press. 2011), pp. 63-86 (p. 66).

<sup>52</sup> Indeed, the implications of community vs. inpatient care are ambiguous. In a recent study, gathering information on the quality of life of patients with severe dementia along with their carers in England, Estonia, Finland, France, Germany, the Netherlands, Spain and Sweden, it was found that in the groups studied, people living in care homes were, in fact, less likely to be depressed than those living and being care for in a community. Clarissa M. Giebel, Caroline Sutcliffe, Anna Renom-Guiteras, Seija Arve, Ingalill Rahm Hallberg, Maria Soto, Adelaida Zabalegui, Jan Hamers, Kai Saks, and David Challis, ‘Depressive symptomatology in severe dementia in a European sample: prevalence, associated factors and prescription rate of antidepressants’, *International Psychogeriatrics*, 26 (2014), 1283 - 93.

the common view of home and community as the ‘natural’ place of care and effortless relationships that are bound by emotions and connection while medicine and cure carry the connotation of knowledge and comprehension of facts.

### *The Paradox of Choice*

In many Northern European countries, such as the Netherlands, Sweden, and Germany, which traditionally experienced a high rate of institutionalisation, the shift towards home-care highlights the trend to emphasise the role of active citizens becoming responsible for themselves, their community, and each other’s wellbeing. These notions form a significant part of new welfare and care policies.<sup>53</sup> At the same time, as individualisation has largely broken down the old traditional structures, the tendency to stress ‘responsabilisation’ now serves to promote independence and self-sufficiency. Meanwhile, responsibility is ideally withdrawn from the state and transferred to the empowered citizens.<sup>54</sup> The question is, however, over what exactly they do gain power? Power, per se, is an empty linguistic shell. As Tonkens and Newman have argued, the true motivations for such policies appear to stem from a desire to reduce costs and decentralise responsibility rather than being an act of empowerment.<sup>55</sup> With government policies increasingly manoeuvring care services out of institutions, ‘home’ as the natural place for care is promoted and care as a public good becomes gradually more privatised. This shift draws in part on the very discourses which a few decades earlier declared institutionalisation as emancipatory actions.<sup>56</sup>

When it comes to disease and issues of exclusion and marginalisation of the chronically ill, the trend to encourage active citizens to take charge of care-duties would require a social, communal structure. Those are the very structures, however, which the mechanisms of institutionalisation and medicalisation in the past centuries have helped to undermine. It could also be maintained that stressing citizens’ involvement and responsibility, whether in care or other formerly public matters, is very much a strategy of policymakers to instruct rather than emancipate or empower.<sup>57</sup> When a few decades ago social movements made every effort to turn the formerly private matters into a public concern thus granting the individuals more rights and a voice, such private matters have now come within the provisions of law and government policies. Along these lines, the citizen’s involvement in care duties would be a means to an

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<sup>53</sup> Suzan Ilcan and Tanya Basok, ‘Community government: voluntary agencies, social justice and the responsabilisation of citizens’, *Citizenship studies*, 8 (2004), 129-44.

<sup>54</sup> Menno Hurenkamp, Evelien Tonkens, Jan Willem Duyvendak, *Crafting Citizenship: Negotiating Tensions in Modern Society*. (Basingstoke: Palgrave Macmillan, 2012), pp. 1-184.

<sup>55</sup> Evelien Tonkens and Janet Newman, ‘Active citizens, activist professionals. The citizenship of new professionals’, in *Participation, responsibility and choice. Summoning the Active Citizen in Western European Welfare States*, ed. by Evelien Tonkens and Janet Newman (Amsterdam: Amsterdam University Press, 2011), pp. 201-216.

<sup>56</sup> Evelien Tonkens, ‘The embrace of responsibility. Citizenship and governance of social care in the Netherlands’, in *Participation, responsibility and choice. Summoning the Active Citizen in Western European Welfare States*, ed. by Evelien Tonkens and Janet Newman (Amsterdam: Amsterdam University Press, 2011), pp. 45-66.

<sup>57</sup> Barbara Cruickshank, *The Will to Empower: Democratic citizens and other subjects* (Ithaca: Cornell University Press, 1990), pp. 1-149.

end and help the state to cope with the conflicts arising from the remodelling of contemporary welfare states. This is achieved by moving responsibility to communities and encouraging healthier lifestyles in environments where healthcare costs are skyrocketing. Control and power, however, remains with the state.<sup>58</sup>

Another cautionary note must be sounded. Paralleling the rise of consumerism during the 1970s and 1980s, patients were equally recast as critical consumers, autonomous decision-makers who are not only in charge of their own life, but also of their own health.<sup>59</sup> The respective policies have redrafted the requests for choice, converting them from collective, solidary to individual, solitary affairs. The patients are to exercise choice over their care provider and the support they receive. At times this can even be to the detriment of others. In this manner, the patients as consumers are thought to be given agency in decisions concerning their bodies and minds. Likewise, the consumer narrative holds great appeal for reforming governments, as it relieves them from certain welfare burdens.<sup>60</sup> In many ways, this attitude has led to a differentiation of care and more personalised approaches in comparison to the principal services, or ‘warehousing’ as Townsend called it, offered before the 1970s.<sup>61</sup>

Yet, the increased priority on autonomy does not necessarily correlate to an increased quality of care. First, a healthcare system entirely shaped by patient autonomy neglects the contributions of the numerous parties concerned, such as family members and caretakers.<sup>62</sup> In palliative care, for instance, the patients do not and cannot live in isolation from these support networks.<sup>63</sup> <sup>64</sup> Second, autonomy requires insight and knowledge. Undeniably, the more one relies on knowledge, the more disadvantaged are those populations who are illiterate, less educated, have disabilities or struggle with language barriers.<sup>65</sup> Third, autonomy necessitates choice, and as we are presented with different options, we are compelled to choose ‘the socially endorsed alternative’.<sup>66</sup> Naturally, the choices we make depend on the information we have access to in our specific cultural and political environment. We frequently end up having to choose from the

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<sup>58</sup> Peris S. Jones, ‘Urban regeneration’s poisoned chalice: is there an Impasse in (Community) Participation Based politics?’, *Urban Studies* 40 (2003), 581-601.

<sup>59</sup> Harlene Anderson and Harold Goolishian, ‘The client is the expert: A not-knowing approach to therapy’, in *Therapy as social construction*. ed. by Sheila McNamee and Kenneth J. Gergen (London: Sage Publications, 1992), pp. 25-39.

<sup>60</sup> John Clarke, Janet Newman, Nick Smith, Elizabeth Vidler, and Louise Westmarland, *Creating Citizen Consumers: Changing publics and changing public services*. (London: Sage, 2007), pp. 1-192.

<sup>61</sup> Peter Townsend, *The Last Refuge: A Survey of Residential Institutions and Homes for the Aged in England and Wales* (London: Routledge and Kegan Paul, 1962), p. 114.

<sup>62</sup> Nolan, *Beyond “person-centred” care*, p. 48.

<sup>63</sup> Judith L. Kissell, ‘The moral self as patient’, in *Ethical foundations of palliative care for Alzheimer’s disease*, ed. by Ruth B. Purtilo and Henk AMJ ten Have (London: John Hopkins University Press, 2004), pp. 131-45.

<sup>64</sup> Henk AMJ ten Have. ‘Expanding the scope of palliative care’, in *Ethical foundations of palliative care for Alzheimer’s disease*, ed. by Ruth B. Purtilo and Henk AMJ ten Have (London: John Hopkins University Press, 2004), pp. 61-79.

<sup>65</sup> Stuckler, *Sick Societies*, p. 96.

<sup>66</sup> Hubbard quoted in Barbara Katz Rothman, ‘The Meanings of Choice in Reproductive Technology’, in *Test-Tube Women: What Future for Motherhood?*, ed. by Rita Arditti, Renate Klein, and Shelley Minden (London: Pandora Press, 1984), pp. 23-33 (p.27).

exact scientific truths or ‘truth regimes’ we were trying to avoid by seeking autonomy in the first place.<sup>67</sup> All these accounts reveal that when it comes to care approaches, complex dynamics are at play. The solutions are never entire, nor are they separable from the cultural, socio-economic, or political environments in which they seek to be implemented. It is within this context that we must assess the emergence of chronic and age-related health conditions, as well as the resulting care approaches devised to cater for the new challenges created by the medical discoveries and improvements we have witnessed in the last centuries.

### *Conclusion*

What I hope to have shown thus far is that there is a latent ambiguity in the oscillation of care between changing notions of community and society. This paper began with an example of a small town. The findings from the community of Roseto illustrated how human relationships can positively influence disease and ageing and how quickly a community’s health status can deteriorate if the social environment changes. Our focus then expanded to the Italian island of Sardinia and other Blue Zones across the globe, where certain close-knit communities appear to hold the magic secret to longevity. I asked how such communities could be replicated, how they could flourish, and whether they offer solutions to the ills of modern ageing societies. Some 19<sup>th</sup> century and mid-20<sup>th</sup> century utopian cohabitation projects provided insights and various forms of commitments and the degree of participation could be identified as key factors. Yet, the chances for the communes’ survival were nonetheless slim. Moreover, we could point to a seeming contradiction, namely that to escape society’s authoritarian grip by forming a new community inevitably leads to a new authoritative structure. lead to ‘successful communities’. This brought us to research which suggested that a caring environment, social support, and positive outlook could potentially help us slow down our biological ageing. And indeed many government policies strive to shift care from institutionalised, inpatient to outpatient, home-based practices. As we have seen, however, such endeavours are at odds with many of the social realities of today’s elderly, and chronically ill in particular, face. If the state relinquishes care responsibilities in the face of growing health costs and an ever-growing medical and pharmaceutical industry, whilst the chronically ill and ageing population continues to increase, how much solidarity is left? If care is delegated back to communities and families in an era of mounting individualism and diminishing community ties, how much care is left? Can one strip the social welfare concept to its foundations and rebuild it with a new, community based core? In practical terms the answer will most certainly be no. In utopian terms it could be yes. The idea of care communities might be the utopian answer to the dystopian woes of an ageing society. Yet, however rosy these utopias may be, they have to date provided little inspiration for the West, wherein the individual is the sole ‘unit of care’, and

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<sup>67</sup>Michel Foucault, *Power/Knowledge: Select Interviews and Other Writings, 1972-1977*, ed. by Colin Gordon, (Brighton: Harveser Press, 1980), p. 113.



the healthcare system is quantified and founded upon autonomy, choice, and freedom at the expense of any notion of community.

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