# 香港百歲老人研究(第二期) Hong Kong Centenarian Study 2

## 研究報告 Project Report

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## **EXECUTIVE SUMMARY**

The question – 'How long can human beings live'? – has fascinated scientists and amateurs alike for millennia. With advances in healthcare and improved living conditions, the population is ageing worldwide. Alongside the aging population is the fast-increasing proportion and population of very old adults. Studies on centenarians have generated valuable information about the process of ageing and degenerative diseases, enabling societies to become more age-friendly and inclusive. Hong Kong, as one of the metropolises with the highest life expectancy, also ranks highly for the density of centenarians. While the population has increased by only 5% in the past decade, the proportion of older adults aged 85 or older rose by 44%, while that of centenarians increased 6-fold. It is therefore imperative and timely to reflect on whether our society is prepared to support the fast-expanding population of very old adults who have contributed so much to building what we enjoy today.

In 2011, our team conducted the first Hong Kong Centenarian Study (HKCS1). In HKCS1, our findings revealed that despite their longevity, near-centenarians and centenarians (NCCs) in Hong Kong face multi-dimensional challenges, including multimorbidity, frailty, poor cognition and financial pressures. Despite our culture's emphasis on family as a source of care, nursing home placement is common among these older adults. HKCS1 generated important scholarly and practical insights about the health and social care needs of the oldest members of our society. We considered it an excellent idea to track the changes in the well-being of successive cohorts of NCCs every decade; therefore, in 2020 we embarked on the second Hong Kong Centenarian Study (HKCS2) supported by the University Grants Committee. Due to the COVID-19 pandemic, we relied on telephone calls with caregivers to learn about NCCs' wellbeing; this offered a unique opportunity to explore how local families care for their oldest members in the community. In HKCS2, we interviewed 151 family caregivers providing care for a relative aged 95 or older. They informed us that:

- Over 75% of NCCs suffered from three or more chronic illnesses, over half presented with frailty.
- Only one in four NCCs were completely autonomous in all six basic activities of daily living.
- Over 70% of the caregivers reported marked cognitive deterioration in their NCC in the past 12 months, and about 40% of NCCs had a diagnosis of dementia.
- Over one-third of NCCs reported social isolation, while caregivers reported that more than a quarter were 'often fearful, anxious, and lonely'.
- While adult children were the key source of income for NCCs, over half of the caregivers experienced financial pressure.
- Caregivers' attitudes towards the use of technologies in providing care to their NCCs were largely favourable, although most used rather 'basic' technologies such as smartphones, electronic blood-pressure-meters, and remote cameras.

Based on these findings, we propose these three key recommendations for health and social care professionals and policymakers:

- 1. Integrate informational support targeting young-old caregivers providing home care to their oldest-old relatives.
- 2. Revamp primary healthcare to provide seamless medico-social integration to ensure accessible management of chronic illness in the community.
- 3. Enhance gerotechnology education, rental, and case management for ageing-in-place.

When we asked our participants what motivated them to care for their ageing parents or spouses at home, one of the most common answers was 'seeing them through'. As researchers, we are humbled by the resilience and wisdom behind the ten decades of life experience of the NCCs, and the commitment of their caregivers. We hope that by adopting an interdisciplinary perspective, our findings will inform stakeholders to adequately prepare Hong Kong to embrace the longevity of our population.

#### **Overview of this report**

This report provides an overview of the findings of HKCS2. In Chapter 1, we elaborate on the distinctiveness of research on centenarians and why these studies are valuable to both scientists and care professionals. In Chapter 2, we describe the methodology of HKCS2. In the subsequent chapters, we elaborate the well-being of NCCs, caregivers and the caregiving experiences using a multidimensional approach, encompassing the physical, psychological and social dimensions. In Chapter 3, we compare the findings from HKCS2 and HKCS1 on key indicators of physical, psychological and social well-being of NCCs. In Chapter 4, we illustrate the well-being of family caregivers. In Chapter 5, we include two cases illustrating the differential use of technologies in family care for NCCs. We conclude this report with policy suggestions in relation to health care, social care, and the development of gerotechnologies for ageing in place in Chapter 6 and 7.

## 摘要

人類壽命的極限是千年來科學家和大眾一直著迷的問題。隨著醫療系統的進步和生活 條件的改善,長者的比例和人口也在快速增長。百歲長者研究亦提供了有關衰老和退 化性疾病相關的寶貴資訊,並使社會變得對長者更友善和包容。香港作為預期壽命最 高的城市之一,在百歲長者密度排行榜上也名列前茅。雖然過去10年人口僅增加5% 左右,但85歲或以上長者的人口比例上升了44%,而百歲長者的人口比例則增加了6 倍。百歲長者為香港社會貢獻半世紀有多,隨着高齡人口快速增長,我們需反思社會 是否已作好準備支援百歲長者。

在 2011 年,我們團隊進行了第一期香港百歲老人研究(下稱第一期研究)。在第一期研 究中,結果顯示香港的近百歲和百歲長者雖然壽命長,卻面臨多方面的挑戰,包括多 種慢性疾病、身體衰弱、認知能力衰退和財務壓力等。儘管我們的文化視家人為主力 照顧者,但安排長者在安老院舍居住仍很常見。第一期研究就這群社會中年齡最高的 成員的健康和社區照顧需求獲得了重要的學術和實踐見解。每十年追蹤歷屆百歲長者 的身心變化是具意義的研究目標,因此在大學教育資助委員會的支持下,我們在 2020 年開始了第二期香港百歲老人研究(下稱第二期研究)。由於新冠肺炎疫情肆虐,我們 透過與照顧者作電話訪問來瞭解百歲長者的健康和心理狀況,而這為我們提供了珍貴 的機會去探索本地家庭如何照顧社區中最年長的成員。在第二期研究中,我們共訪問 了 151 名正照顧 95 歲或以上親屬的家庭照顧者。從他們的分享中,我們發現:

- 超過75%近百歲和百歲長者患有3種或以上的慢性疾病,其中多於一半長者有身體 衰弱的情況。
- 只有4分之1的近百歲和百歲長者在所有6項基本日常生活活動中能夠獨立自理。
- 超過 70%照顧者表示在過去 12 個月中,他們的近百歲和百歲長者有明顯的認知退化,大約 40%近百歲和百歲長者被診斷患有認知障礙症。
- 超過3分之1照顧者留意到近百歲和百歲長者有社會孤立的狀況,而超過4分之1 長者經常感到「恐懼,焦慮和孤獨」。
- 成年子女的經濟支援是近百歲和百歲長者的主要收入來源,但超過一半的照顧者表 示有經濟壓力。
- 照顧者對使用科技照顧近百歲和百歲長者持較為正面的態度,但大多數照顧者使用 較為「基本」的科技,如智能手機,血壓計和遙控鏡頭。

基於上述發現,我們為醫療和社福專業人士和政策制定者提出了以下3項關鍵建議:

- 1. 整合正照顧年老親屬的初老照顧者所需要的資訊及服務。
- 2. 改善基層醫療服務,實現無縫的醫社合作,促進以社區為本的慢性疾病支援。
- 3. 推動為居家安老而設的樂齡科技教育、租賃和個案管理。

當我們詢問照顧者促使他們繼續照顧年邁父母或配偶的原因時,「陪伴終老」是最常見的答案之一。作為研究員,我們欽佩長者百年人生背後的智慧和韌力,以及照顧者不離不棄的陪伴。本研究希望透過跨學科的視角,為不同持份者提供數據,讓香港成為以長壽為榮的社會。

#### 本報告概述

本報告概述第二期研究的調查結果。在第1章中,我們詳細闡述了百歲老人研究的獨 特性,以及為什麼這些研究對科學家和相關專業人員都很有價值。在第2章中,我們 描述了第二期的研究方法。在隨後的章節(第3章至7章)中,我們使用跨學科的視 覺,以身體、心理和社交健康的角度闡述了近百歲和百歲長者、照顧者的狀況,和他 們的照顧經驗。在第3章中,我們比較了第一期和第二期的近百歲和百歲長者在身 體、心理和社會福祉等關鍵指標上的調查結果。第4章闡述了家庭照顧者的幸福感。 在第5章中,我們納入了兩個案例分享,說明如何使用不同科技居家安老。本報告的 最後章節提出與醫療保健、社區照顧和本地樂齡科技發展的相關政策建議。

## **CHAPTER 1 PROJECT BACKGROUND AND OBJECTIVES**

#### Centenarians - a new common sight in ageing population.

The worldwide population is ageing at an unprecedented rate due to enhanced access to quality healthcare and improved living conditions. In aging societies, the proportion of oldest-old adults is expanding more quickly than younger cohorts<sup>1</sup>. Alongside this trend has been a continued increase in the proportion of centenarians, especially in developed regions<sup>1</sup>. One in two children born after the year 2000 can expect to reach age 100<sup>2</sup>, and the global population of centenarians is predicted to double in the next decade<sup>3</sup>.

The United Nations estimated there were 593,166 centenarians worldwide in 2021, up from 329,721 in 2011, and the population is predicted to reach 21.56 million by the end of the century<sup>3</sup>. In the past, scientists thought that centenarians were a privilege of the "Longevity Blue Zones" – Okinawa (Japan), Sardinia (Italy), Nicoya (Costa Rica), Icaria (Greece) and Loma Linda (California, USA). As population ageing accelerates, centenarians have become a common sight in most metropolises.

While global average life expectancy is about 71.4 years, Hong Kong heads the life expectancy charts with a record high of 85.5 years<sup>4</sup>. As expected, Hong Kong is also a location where individuals are most likely to live to be 100. Among every 100,000 residents, 47 had reached 100 years old in 2020, coming in behind Japan (62 centenarians per 100,000 people)<sup>5</sup>. In 2021, the number of centenarians in Hong Kong was estimated to be 11,575 (out of a population of 7.41 million), up from 289 (out of 4.98 million people) in 1981, and about 1,890 in 2011 (out of a population of 7.07 million).

Centenarians not only show scientists what the longevity prototype and genotype look like, but they also challenge the basic assumptions of the science of well-being. Despite the unfavourable ramifications of biological ageing, many centenarians continue to live a satisfying life. As the epitome of longevity, centenarians offer distinct opportunities for biological scientists to study the processes behind ageing and degenerative diseases. The findings of centenarian studies also illustrate the care needs of the frailest, but often most resilient, population cohorts, enabling societies to be more age-friendly and inclusive. Hence, centenarian studies have been conducted all over the world – in Asia-Pacific (e.g., Australia, China, Japan, Korea, Singapore), Europe (e.g., Denmark, France, Germany, Italy, Portugal, Sweden, the United Kingdom), and Americas (e.g., Costa Rica, the United States). Our team conducted the first study on centenarians in Hong Kong in 2011<sup>6</sup>. Based on our previous work,

<sup>&</sup>lt;sup>1</sup> United Nations. (2015). *World population prospects: 2015 revision*. [cited 2023 Apr 13]. Available from: http://www.un.org/en/development/desa/publications/world-population-prospects-2015-revision.html)

<sup>&</sup>lt;sup>2</sup> Christensen, K., Doblhammer, G., Rau, R., & Vaupel, J.W. (2009) Ageing populations: The challenges ahead. *Lancet, 2019* (374), 1196-1208.)

<sup>&</sup>lt;sup>3</sup> United Nations. (2022). *Population division world population prospects 2022*. New York: United Nations. Online Edition.

<sup>&</sup>lt;sup>4</sup> United Nations Development Programme. (2022). *Human development report 2021-22: Uncertain times, unsettled lives: Shaping our future in a transforming world.* New York: United Nations.

<sup>&</sup>lt;sup>5</sup> Lin, E. (2022, July 11). Hong Kong ranks 7th among places where people are most likely to live beyond 100 years. *South China Morning Post*.

<sup>&</sup>lt;sup>6</sup> Lau, B.H.P., & Cheung, K.S.L. (2015). Hong Kong Centenarian Study. In Pachana N, editor. *Encyclopedia of geropsychology*. Singapore: Springer.

the current study – the Hong Kong Centenarian Study 2 (HKCS2) - examined how communitydwelling near-centenarians and centenarians (NCCs) and their family caregivers have adapted to the multidimensional challenges in their everyday lives, especially during the multiple COVID-19 outbreaks.

## Distinctive challenges and resources of centenarians.

Although scientists have anticipated that the same factors for longevity may have also facilitated the well-being of people who live to the tenth decade of their lives<sup>7</sup>, survivorship to age 80 is often qualitatively different from survivorship from 80 to 100 years or older<sup>8</sup>. Although most NCCs have escaped the most lethal diseases (e.g., cancers), the overwhelming majority live with multiple chronic diseases (e.g., heart disease, osteoarthritis, dementia)<sup>9</sup>. Centenarians are more likely to be on prescribed medication, hospitalized, and utilize more medical services than sexagenarians or octogenarians<sup>10</sup>.

Frailty, meaning diminishing biological reserve to protect a person against stressors, is common in NCCs, and tends to co-occur with poor functional, objective, and subjective health outcomes<sup>11</sup>. Furthermore, centenarians tend to report fewer social resources than their peers in their 60s and 80s, one reason being that they have outlived most of their spouses, peers, and even children<sup>12</sup>. Exceptional longevity also often leaves them as the sole surviving member among their contemporaries, thereby exposing them to heart-breaking losses, dwindling social networks, and disengagement from the fast-changing, no-longer familiar world.

Paul Baltes<sup>13</sup> postulated the period of oldest-old age as a time of incomplete compensation by psychosocial resources for the inevitable declines of physical health and functional capacity. However, the "paradox of aging", suggests that the deterioration of objective health tends to

<sup>&</sup>lt;sup>7</sup> Fries, J. F. (2005). The compression of morbidity. *The Milbank Quarterly*, 83(4), 801–823.

<sup>&</sup>lt;sup>8</sup> Martin, P., Hagberg, B., & Poon, L. W. (2012). Models of studying centenarians and healthy aging. *Asian Journal of Gerontology and Geriatrics*, *7*, 14-18.

 <sup>&</sup>lt;sup>9</sup> Evert, J., Lawler, E., Bogan, H., & Perls, T. (2003). Morbidity profiles of centenarians: Survivors, delayers, and escapers. *The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences, 58*(3), 232–237.
 <sup>10</sup> Poon, L. W., Jazwinski, M., Green, R. C., Woodard, J. L., Martin, P., Rodgers, W. L., Johnson, M. A.,

<sup>Hausman, D., Arnold, J., Davey, A., Batzer, M. A., Markesbery, W. R., Gearing, M., Siegler, I. C., Reynolds, S., & Dai, J. (2007). Methodological considerations in studying centenarians: Lessons learned from the Georgia Centenarian Studies.</sup> *Annual Review of Gerontology & Geriatrics*, 27(1), 231–264.

<sup>&</sup>lt;sup>11</sup> Lau, B. H., Kwan, J., & Cheung, K. S. (2016). Overlap of frailty, comorbidity, disability, and poor self-rated health in community-dwelling near-centenarians and centenarians. *Journal of the American Geriatrics Society*, *64*(4), 900–901. https://doi.org/10.1111/jgs.14063

<sup>&</sup>lt;sup>12</sup> Randall, G. K., Martin, P., Bishop, A. J., Poon, L. W., & Johnson, M. A. (2011). Age differences and changes in resources essential to aging well: A comparison of sexagenarians, octogenarians, and centenarians. *Current Gerontology and Geriatrics Research*, 357896. https://doi.org/10.1155/2011/357896

<sup>&</sup>lt;sup>13</sup> Baltes P. B. (1997). On the incomplete architecture of human ontogeny. Selection, optimization, and compensation as foundation of developmental theory. *The American Psychologist*, *52*(4), 366–380. https://doi.org/10.1037//0003-066x.52.4.366

lag behind a subjective assessment among people of advanced age<sup>14</sup>. While centenarians with no chronic disease are rare, centenarians who continue to live a satisfying life are not<sup>15,16</sup>.

Studies on the lived experience of centenarians have illustrated the strategies they use to adapt to the increasing limitations of their life-space due to their advanced age. Our previous study revealed the significance of maintaining a positive psychological outlook for achieving successful aging among local NCCs. We also found that healthy local centenarians capitalize on their positive social relationships, their collection of positive memories, and salutary life values (e.g., fatalism, gratitude, stoicism, kindness, work ethic) to maintain happiness in old age<sup>5</sup>. The personalities of centenarians tend to be hardy, audacious, open to new experiences, conscientious, and uncompromising<sup>6, 17</sup>. Such a personality profile may reflect a rich history of surviving, and even thriving, through life's stressors.

## Caregiving for centenarians in the community

While most family caregiving models assume the caregiving responsibility with healthy middle-aged adult children or a same-age spouse, in the case of NCCs their spouses may have died, while their children are themselves relatively younger older adults. Caregiving burdens may be shared across several generations (including grandchildren), or even reversing the caregiver-care recipient relationship (i.e., healthy NCCs caring for sick mid-old children). Knowledge of the strains and strengths of familial care in families with NCCs remains elusive<sup>18</sup>.

However, existing studies on caregiving for centenarians show distinctive challenges for these caregivers<sup>19, 20, 21</sup>.

First, while it is a laudable mission to see one's parents of advanced age through highs and lows, the children of NCCs themselves are undoubtedly older adults and find caregiving tasks,

 <sup>&</sup>lt;sup>14</sup> Galenkamp, H., Deeg, D. J., Huisman, M., Hervonen, A., Braam, A. W., & Jylhä, M. (2013). Is self-rated health still sensitive for changes in disease and functioning among nonagenarians? *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences, 68*(5), 848–858. https://doi.org/10.1093/geronb/gbt066
 <sup>15</sup> Andersen-Ranberg, K., Schroll, M., & Jeune, B. (2001). Healthy centenarians do not exist, but autonomous centenarians do: a population-based study of morbidity among Danish centenarians. *Journal of the American Geriatrics Society, 49*(7), 900–908. https://doi.org/10.1046/j.1532-5415.2001.49180.x

 <sup>&</sup>lt;sup>16</sup> Cho, J., Martin, P., & Poon, L. W. (2012). The older they are, the less successful they become? Findings from the Georgia Centenarian Study. *Journal of Aging Research*, 2012, 695854. https://doi.org/10.1155/2012/695854
 <sup>17</sup> Census and Statistics Department. (2021). *Hong Kong 2021 population census - main results*. Hong Kong: Census and Statistics Department. Available from:

https://www.censtatd.gov.hk/en/EIndexbySubject.html?pcode=B1120109&scode=600

<sup>&</sup>lt;sup>18</sup> Motta, M., Bennati, E., Ferlito, L., Malaguarnera, M., Motta, L., & Italian Multicenter Study on Centenarians (IMUSCE) (2005). Successful aging in centenarians: myths and reality. *Archives of Gerontology and Geriatrics*, 40(3), 241–251. https://doi.org/10.1016/j.archger.2004.09.002

<sup>&</sup>lt;sup>19</sup> Eggert, S., Wenzel, A., Suhr, R., Gellert, P., & Dräger, D. (2021). Caregiving adult children's perceptions of challenges relating to the end of life of their centenarian parents. *Scandinavian Journal of Caring Sciences*, *35*(4), 1086–1095. https://doi.org/10.1111/scs.12921

<sup>&</sup>lt;sup>20</sup> Macedo, T., Sousa, L., & Ribeiro, O. (2022). Aged 70 and still a child: complexities, strains and gains of older children caring for their (near) centenarian mothers. *Age and Ageing*, *51*(1), afab204. https://doi.org/10.1093/ageing/afab204

<sup>&</sup>lt;sup>21</sup> Boerner, K., Jopp, D. S., Park, M. K., & Rott, C. (2016). Whom do centenarians rely on for support? Findings From the Second Heidelberg Centenarian Study. *Journal of Aging & Social Policy*, *28*(3), 165–186. https://doi.org/10.1080/08959420.2016.1160708

especially those requiring physical strength and mental vigilance, effortful, too. Coupled with the lack of access to information resources and community support, many of these older caregivers suffer from significant caregiving burdens and are left helpless. Also, the caregivers need to witness the ageing-related decline of their oldest-old relatives, which is often a disheartening experience, but also the prognosis of their own future. Such 'double confrontation' can be perceived as a unique opportunity to learn and prepare for one's own old age, but also a burden that dissipates compassion toward the care recipient.

Technologies have great potential for enhancing the quality of life of older adults with compromised mobility, physical health, and social resources, and that of their caregivers. Information and communication technologies help reconnect older adults to their loved ones who live at a distance, keep them informed of what is happening in their community, monitor their health, render services more accessible, and improve the safety of their living environment<sup>22</sup>.

Assistive devices may support older adults to live independently by fostering home safety, supporting activities of daily living, thereby reducing caregiver strains and possibly premature institutionalization. These technologies have also proven to be effective solutions for caregivers by increasing efficiency, improving levels of assistance, reducing anxiety, lowering the difficulty of tasks, and reducing safety risks<sup>23</sup>. However, areas of care where technologies may effectively intervene, receptiveness to technologies, and current usage patterns are largely unknown with respect to ageing-in-place for oldest-old adults.

#### **Research objectives**

In addition to tracking the well-being and care needs of successive cohorts of NCCs in Hong Kong, HKCS2 was conducted during multiple COVID-19 outbreaks, therefore, documenting the livelihood of NCCs and their caregivers during the pandemic. Hence, besides investigating the physical, functional, psychological, and social well-being of older adults born in or before 1927, by interviewing their caregivers, we also examined the caregiving burdens, gains, attitudes, and the use of technologies in caregiving among caregivers providing family care to community-dwelling NCCs.

<sup>&</sup>lt;sup>22</sup> Heinz, M., Cho, J., Kelly, N., Martin, P., Wong, J., Franke, W., Hsieh, W.H., & Blaser, J. (2016). The potential of three computer-based communication activities for supporting older adult independent living. *Information*, 7(2), 26. https://doi.org/10.3390/info7020026

<sup>&</sup>lt;sup>23</sup> Madara Marasinghe K. (2016). Assistive technologies in reducing caregiver burden among informal caregivers of older adults: a systematic review. Disability and rehabilitation. *Assistive Technology*, 11(5), 353–360. https://doi.org/10.3109/17483107.2015.1087061

## **CHAPTER 2 METHODOLOGY**

#### Sampling and procedures

This study included 151 families with older adults passing their 95th birthday by the time of data collection (i.e., born in 1927 or before). Their primary family caregivers were interviewed primarily by phone to answer a battery of questionnaires regarding the demographic characteristics, physical, functional, psychological, and social well-being of the NCCs, and their caregiving experience. Quota sampling was employed according to the proportion of adults aged 85 or above by the 18 Geographical Constituency Areas in 2020 to recruit a geographically representative sample. Eligible interviewees were (i) a family member of a community-dwelling Hong Kong Chinese older adult aged 95 or above, (ii) able to communicate in Cantonese, and (iii) a Hong Kong resident. Eligible families were recruited through community care and support service networks for older adults provided by 31 Non-Governmental Organizations (NGOs) and related units in Hong Kong. Phone interviews were arranged by the research assistant within two weeks after the eligible caregiver expressed an interest in participating. Informed consent was obtained from the family caregivers as they were the interviewees. Each phone interview took around 60 to 90 minutes to complete. This study was approved by the Human Research Ethics Committee of Hong Kong Shue Yan University (HREC-19-05-F06). Data collection was conducted between April 2021 and September 2022.

#### **Quantitative instruments**

*NCCs*. The quantitative measurements of NCCs were based on the Chinese Longitudinal Healthy Longevity Survey (CLHLS) and the HKCS1 questionnaires. Besides demographics (e.g., gender, age, place of birth, education, parity, no. of siblings, marital status, previous occupation, religion, etc), the following instruments were used to assess NCCs' physical, functional, psychological, and social well-being:

*Physical health*: Caregiver-rated health, number of chronic illnesses, episodes of fall and hospitalization, body-mass index, appetite, sleep quality, recent physical discomforts, no. of medication, healthcare expenditure, and service usage.

*Functional health*: Katz basic activities of daily living<sup>24</sup>, Lawton-Brody instrumental activities of daily living<sup>25</sup>, frequencies of activities (exercising, household chores, hobbies, personal outdoor activities)

Psychological well-being: Big-5 personality by Ten Item Personality Inventory<sup>26</sup>,

<sup>&</sup>lt;sup>24</sup> Katz, S., Ford, A. B., Moskowitz, R. W., Jackson, B. A., & Jaffe, M. W. (1963). Studies of illness in the aged: The index of ADL: A standardized measure of biological and psychosocial function. *Journal of the American Medical Association*, *185*(12), 914-919

<sup>&</sup>lt;sup>25</sup> Lawton, M.P., & Brody, E.M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. *The Gerontologist*, *9*(3), 179-186

<sup>&</sup>lt;sup>26</sup> Gosling, S. D., Rentfrow, P. J., & Swann Jr, W. B. (2003). A very brief measure of the Big-Five personality domains. *Journal of Research in Personality*, *37*(6), 504-528.

Patient Health Questionnaire-4 for anxiety and depression <sup>27</sup>, positive affect (tidiness, happiness, autonomy, optimism), negative affect (ear, perceived uselessness, loneliness).

Social well-being: Lubben Social Network Scale<sup>28</sup>, frequencies of social activities

Service utilization and financial well-being: Utilization of social care services, key source of income, adequacy of income and receipt of subsidies and allowances.

*Caregivers*. Besides demographics (gender, age, income, education, religion, marital status), co-residence with the NCC and the presence of domestic helpers were also documented. In addition, well-being, caregiving burden, caregiving gains and attitudes to gerotechnologies were collected with the following:

*Well-being*: Self-rated health, number of chronic illnesses, episodes of fall, and hospitalization, Patient Health Questionnaire-4 for anxiety and depression<sup>27, 28</sup>.

*Caregiving burden*: Zarit Burden Interview 4-item version<sup>29</sup>, perceived bother and burdens of caregiving task, weekly hours of caregiving.

Caregiving gains: Positive Aspects of Caregiving 5-item version<sup>30</sup>.

*Gerotechnologies*: Attitudes towards the use of technologies in caregiving (perceived usefulness, perceived ease of use, financial support, social support), use of technologies in caregiving for NCCs (product category, duration of usage)

## Qualitative interview

Towards the end of each phone interview, caregivers were asked the following open-ended questions:

- 1. What are the biggest challenges and rewards in your care for the NCCs?
- 2. How do you think technologies may impact or have impacted your care for the NCCs?
- 3. Did the COVID-19 pandemic impact your care for the NCCs? If so, how?

<sup>&</sup>lt;sup>27</sup> Kroenke, K., Spitzer, R. L., Williams, J. B., & Löwe, B. (2009). An ultra-brief screening scale for anxiety and depression: The PHQ-4. *Psychosomatics*, *50*(6), 613–621. https://doi.org/10.1176/appi.psy.50.6.613

<sup>&</sup>lt;sup>28</sup> Lubben, J., Blozik, E., Gillmann, G., Iliffe, S., von Renteln Kruse, W., Beck, J. C., & Stuck, A. E. (2006).

Performance of an abbreviated version of the Lubben Social Network Scale among three European communitydwelling older adult populations. *The Gerontologist*, 46(4), 503-513.

<sup>&</sup>lt;sup>29</sup> Bédard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit Burden Interview: A new short version and screening version. *The Gerontologist*, *41*(5), 652-657.

<sup>&</sup>lt;sup>30</sup> Savundranayagam, M. Y., Montgomery, R. J., & Kosloski, K. (2011). A dimensional analysis of caregiver burden among spouses and adult children. *The Gerontologist*, *51*(3), 321-331.

## CHAPTER 3 CHARACTERISTICS OF NEAR-CENTENARIANS AND CENTENARIANS (NCC)

## 3.1 Demographic characteristics

This study included data from 151 families with older adults passing their 95th birthday by the time of data collection. Age was validated by both the caregiver's knowledge and the NCC's Hong Kong identity card. *Figures 1* and 2 demonstrate the gender ratio and age distribution of the NCCs. About three-quarters (75.5%) were female. Their mean age was 97.6 (SD=2.51), ranging from 95 to 106, with a majority (80.1%) being near-centenarians aged between 95 and 99.

Figure 1. Gender of the near-centenarians and centenarians (NCCs) (N=151)



Figure 2. Age distribution of the near-centenarians and centenarians (NCCs) (N=151)



*Table 1* lists NCCs' socio-demographic characteristics. They were mainly born in Mainland China (84.1%), primarily from Guangdong province. Most NCCs lived with a family member

(76.2%), while 30.5% lived with both a family member and one or more domestic helpers. Only 9.3% lived alone. About half (49.3%) lived in public housing, and the other half (49.6%) lived in private housing, either owned or rented. Most NCCs were bereaved (81.5%), and only 17.9% had a spouse still living. Half had not received any formal education (50.0%) or had only received one to five years of education (24.0%). Most NCCs believed in folk religion (35.1%) or had no religious belief (25.0%). A quarter (26.4%) were employed in the handicraft industry when they were young, followed by working as unskilled labourers (25.7%) or unengaged in economic activities (23.6%).

	Near-Centenarians and Centenarians
	(NCCs)
	N (%)
Place of birth (N=151)	
Hong Kong	16 (10.6)
Mainland China	127 (84.1)
Others <sup>a</sup>	8 (5.3)
Living arrangements (N=151)	
Living alone	14 (9.3)
Living with family	115 (76.2)
Living with domestic helper(s) only	20 (13.2)
Living in hospital / care facilities	2 (1.3)
(temporary)	
Housing (N=151)	
Public housing	74 (49.0)
Private housing (brought)	68 (45.0)
Private housing (rent)	7 (4.6)
Others (e.g. Housing for the Elderly)	2 (1.3)
Marital status (N=148, Missing=3)	
Married	25 (17.9%)
Bereaved	123 (81.5%)
Divorced	0 (0.0%)
Never married	1 (0.7%)
Educational Level (N=146, Missing=5)	
None	73 (50.0%)
1 to 5 years	35 (24.0%)
Primary school	22 (15.1%)
Some high school	8 (5.5%)
High school diploma	5 (3.4%)
Post-secondary / Tertiary education	3 (2.1%)
Religions (N=148, Missing=3)	
Christianity	25 (16.9)

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Catholicism	14 (9.5)			
Buddhism	15 (10.1)			
Taoism	4 (2.7)			
Folk religion	52 (35.1)			
No religious belief	37 (25.0)			
Others	1 (0.7)			
Occupation (N=148, Missing=3)				
Professional	4 (2.7)			
Auxiliary professional	1 (0.7)			
Clerk	2 (1.4)			
Service and retail	13 (8.8)			
Agriculture and fisheries	6 (4.1)			
Handicraft industry	39 (26.4)			
Unskilled laborer	38 (25.7)			
Others	10 (6.8)			
Unengaged in Economic Activities	35 (23.6)			
<sup>a</sup> Others include Thailand, Macao, Vietnam, Southeast Asia and Singapore				

*Figure 3* shows the number of children NCCs had. Almost half (48.6%) had between four and six children; the mean number of children was 4.42 (SD 2.05), ranging from 1 to 11.

Figure 3. Number of children of near-centenarians and centenarians (NCCs) (N=148)



## **3.2 Intrinsic capacity**

The World Health Organization (WHO) has proposed Healthy Ageing as cultivating and preserving the functional capacity necessary to promote well-being during the later stages of life<sup>31</sup>.

Under this framework, intrinsic capacity encompasses both the physical and mental abilities that interplay with a person's environment to affect healthy ageing. Intrinsic capacity comprises cognition, mobility, psychological well-being, vitality, and sensory functions. These capacities determine a person's ability to complete basic activities of daily living independently. The WHO's Healthy Ageing model, which adopts a life course approach, highlights that early changes often precede physical and functional decline in old age<sup>32</sup>.

## (I) Vitality

Vitality refers to the physiological capacity of intrinsic capacity. The construct indicates the state of one's physiological reserve as a result of normal and pathological ageing, reflected in the interplay between different physiological systems, energy and metabolism, neuromuscular function, and immunity<sup>33</sup>.

## Chronic illness and comorbidity

The Charlson Comorbidity Index (CCI)<sup>34</sup> was used to evaluate the burden of comorbidities. NCCs' mean CCI score was 5.0 (SD=1.1), and the average number of chronic illnesses was 2.9 (SD=1.6). *Figure 4* displays the number of chronic illnesses among NCCs. Half (46.6%) had three to four chronic illnesses. Close to 75% had three chronic illnesses or more, while only 0.7% were free of any chronic illnesses. The most prevalent chronic illnesses were high blood pressure (67.3%), cardiovascular diseases (37.5%), cataracts (32.0%), and osteoporosis (28.0%). Only 2.7% of NCCs were cancer survivors.

<sup>&</sup>lt;sup>31</sup> Michel, J. P., & Sadana, R. (2017). "Healthy aging" concepts and measures. *Journal of the American Medical Directors Association*, *18*(6), 460–464. https://doi.org/10.1016/j.jamda.2017.03.008

<sup>&</sup>lt;sup>32</sup> Zhou, Y., & Ma, L. (2022). Intrinsic capacity in older adults: Recent advances. *Aging and Disease, 13*(2), 353–359. https://doi.org/10.14336/AD.2021.0818.

<sup>&</sup>lt;sup>33</sup> Bautmans, I., Knoop, V., Amuthavalli Thiyagarajan, J., Maier, A. B., Beard, J. R., Freiberger, E., Belsky, D., Aubertin-Leheudre, M., Mikton, C., Cesari, M., Sumi, Y., Diaz, T., & Banerjee, A. (2022). WHO working definition of vitality capacity for healthy longevity monitoring. *The Lancet. Healthy Longevity, 3*(11), e789–e796. https://doi.org/10.1016/S2666-7568(22)00200-8.

<sup>&</sup>lt;sup>34</sup> Charlson, M. E., Pompei, P., Ales, K. L., & MacKenzie, C. R. (1987). A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *Journal of Chronic Diseases, 40*(5), 373-383.



*Figure 4. Number of chronic illnesses among near-centenarians and centenarians (NCCs) (N=148)* 

## Frailty

Based on a phenotypical approach to frailty, the FRAIL scale was adopted. The FRAIL scale comprises five items: fatigue, resistance, ambulation (mobility), illnesses, and weight loss, and has a possible score ranging from 0 to 5 (i.e., 0 = non-frail, 1-2 = pre-frail, 3 or above = frail)<sup>35</sup>.

*Figure 5* illustrates the prevalence of frailty among NCCs. 55.3% were frail, 39.0% were prefrail, and only 5.7% of NCCs retained a robust health status.

Figure 5. Frailty status among near-centenarians and centenarians (NCCs) (N=141)



#### Hospitalization and medicine usage

Slightly more than half (57.6%) of NCCs had not been hospitalized in the previous two years. Regarding medication usage among NCCs, the average number of prescribed medications NCCs had to take daily was 3.28 (SD=2.24); 26.5% of NCCs were taking more than four prescribed medications per day (*Figure 6*).

<sup>&</sup>lt;sup>35</sup> Van Kan, G. A., Rolland, Y., Bergman, H., Morley, J. E., Kritchevsky, S. B., & Vellas, B. (2008). The I.A.N.A. task force on frailty assessment of older people in clinical practice. *The Journal of Nutrition, Health & Aging, 12*(1), 29–37. https://doi.org/10.1007/BF02982161.

## Figure 6. Number of prescribed medications taken by NCCs per day (N=147)



## Nutrition and appetite

Only 17.6% of NCCs experienced a significant weight loss of 3 kg or more in the previous six months, while 14.6% reported poor appetite. Regarding dental status, the average number of remaining teeth NCCs had was 3.16 (SD=5.0), and about 75% wore dentures.

## Smoking and alcohol consumption

Most NCCs had never smoked in their lifetime (79.7%); a small proportion of NCCs (19.6%) had smoked at some time in their life but had already quit. Only one NCC was still smoking at the time of data collection. A similar pattern was found for alcohol consumption . Over 80% had never consumed alcohol, and only 15.5% had drunk alcohol at some time in their life but had now quit. Only 2.7% continued to drink at such an old age.

## (II) Locomotion

Locomotion was measured by the NCC's ability to walk (i) 400 meters on a flat surface or (ii) up a flight of stairs without any assistance from an assistive device or a person. Only 15.9% of NCCs were able to walk 400 meters without any assistance, and only 13.2% could walk up a flight of stairs independently. About half (48.3%) were able to move around indoors in their residence without the help of a cane or walking device. Regarding the risk of falling, only a small proportion (18.1%) had experienced falling in the six months preceding data collection.

## (III) Sensory function

About half of the NCCs (45.7%) were visually impaired even with spectacles, while 59.6% were hearing impaired even with a hearing device.

## (IV) Psychological well-being

## Positive and negative psychological states

NCCs' psychological was measured by the seven items used in the Chinese Longitudinal Healthy Longevity Study (CLHLS)<sup>36</sup>, four tapping positive psychological states, and three measuring negative psychological states. Caregivers were asked to indicate whether their NCCs exhibited each psychological state by answering "1 = Yes" or "0 = No". Over half of the caregivers responded "Yes" to the four items assessing positive psychological states, with the largest proportion (83.6%) indicating that their NCCs preferred to keep things clean and tidy (*Figure 7*). In contrast, the smallest proportion of caregivers (57.5%) agreed that their NCCs felt as happy as they did when they were young. More than half (62.3%) of the caregivers agreed that their NCCs felt less useful as they grew older. Additionally, 27.4% of caregivers agreed that their NCCs often felt anxious and fearful, while 26.7% agreed that their NCCs felt lonely (*Figure 8*).

*Figure 7. Psychological well-being of the near-centenarians and centenarians (NCCs) (N=146)* 



Notes: The numbers contained within the bars indicate the frequency of occurrences for each respective category.

<sup>&</sup>lt;sup>36</sup> Yi, Z. (2008). Introduction to the Chinese Longitudinal Healthy Longevity Survey (CLHLS). In: Yi, Z., Poston, D.L., Vlosky, D.A., Gu, D. (eds) *Healthy longevity in China*. The Springer Series on Demographic Methods and Population Analysis, vol 20. Springer, Dordrecht. https://doi.org/10.1007/978-1-4020-6752-5\_2.



*Figure 8. Negative psychological well-being of the near-centenarians and centenarians (NCCs) (N=146)* 

#### **Depression and Anxiety**

The four-item Patient Health Questionnaire (PHQ-4)<sup>27</sup> was adopted to measure caregiver-rated depression and anxiety symptoms of NCCs. PHQ-4 consists of four items that assess the frequency of symptoms experienced over the past two weeks, with two items assessing depression (e.g., "little interest or pleasure in doing things") and two items assessing anxiety (e.g., "feeling nervous, anxious, or on edge"). Caregivers rated the frequency of each symptom on a 4-point scale (0 = not at all, 1 = several days, 2 = more than half the days, 3 = nearly every day). *Table 2* shows the distribution of responses in each item.

Table 2.	Distribution	of responses	in each ite	em in the fo	our-item Pati	ent Health
Question	naire (N=14	(2)				

Items	Not at all (0)	Several days (1)	More than half the days (2)	Nearly every day (3)
Feeling nervous, anxious or on edge	87 (61.3)	39 (27.5)	9 (6.3)	7 (4.9)
Not being able to stop or control worrying	103 (72.5)	26 (18.3)	10 (7.0)	3 (2.1)
Feeling down, depressed or hopeless	107 (75.4)	22 (15.5)	7 (4.9)	6 (4.2)
Little interest or pleasure in doing things	69 (45.7)	25 (17.6)	17 (12.0)	31 (21.8)

*Figure 9* illustrates the distribution of NCCs' scores for the Depression and Anxiety Scale in PHQ-4, based on the cut-off score of  $\geq$ 3 for the first two questions suggesting probable anxiety and a total score of  $\geq$ 3 for the last two questions suggesting probable depression<sup>27</sup>. The proportion of NCCs showing probable anxiety was 10.6% and the proportion showing probable depression was 28.9%.

*Figure 9. Distribution of NCCs' scores on the Depression and Anxiety Scale (PHQ-4)* (*N*=142)



Notes: A score of 3 or higher on the depression and anxiety scale require clinical attention.

## (V) Cognition

A diagnosis of dementia was found in 37.7% of NCCs. Caregivers also perceived that 71.9% of NCCs experienced an observable decline in cognitive performance over the past year, while 24.7% maintained the same level of performance, and only 3.4% showed an improvement (*Figure 10*).

Figure 10. 1 year-deterioration in cognitive performance among NCCs (N = 146)



## (VI) Medical service usage

*Table 3* presents the average number of medical services utilized by NCCs in the past year. On average, NCCs utilized 6.99 (SD=6.37) different medical services annually. Most NCCs used specialist medical services (Mean=4.07, SD=2.88), followed by family doctors (Mean=1.73, SD=3.04) and Chinese medicine (Mean=1.10, SD=4.98). In terms of medical care expenses, average spending was approximately HKD\$4000, ranging from HKD\$0 to HKD\$55,000. Most expenditure was supported by a healthcare voucher.

Medical Services	Mean	SD	Range
Family doctor	1.73	3.04	0-20
Specialist medical service	4.07	2.88	0-16
Chinese medicine	1.10	4.98	0-52
Chiropractic	0.06	0.44	0-4
Dentist	0.09	0.33	0-2
Overall	6.99	6.37	0-59

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Consensus regarding the measurement of different components of intrinsic capacity remains elusive<sup>37</sup>, especially regarding oldest-old adults. However, we found significant proportions of NCCs suffering from multi-comorbidities, frailty, polypharmacy, mobility difficulties, and sensory impairment that would have affected their ability to live an autonomous life in the community. Caregivers also observed and reported significant psychological distress, especially loneliness and depressive symptoms, and cognitive decline among their older relatives, possibly due to the COVID restrictions.

## **3.3 Functional health and daily activities**

## (I) Activities of daily living (ADL)

*Figure 11* illustrates the level of independence in six activities of daily living (ADL) among NCCs, namely bathing, dressing, toileting, transferring indoors, continence, and feeding. Continence was the most preserved function; 65.3% of NCCs managed this without any assistance, followed by toileting (60.0%) and dressing (50.3%). In contrast, bathing was the activity that the lowest proportion of NCCs (46.0%) could complete independently. On average, NCCs could complete 3.23 (SD = 2.24) ADLs independently, with a range of 0 to 6. Only 23.5% could complete all ADLs (bathing, dressing, toileting, indoor transfer, continence, and feeding) without any assistance.

<sup>&</sup>lt;sup>37</sup> George, P. P., Lun, P., Ong, S. P., & Lim, W. S. (2021). A rapid review of the measurement of intrinsic capacity in older adults. *The Journal of Nutrition, Health & Aging, 25*(6), 774–782. https://doi.org/10.1007/s12603-021-1622-6.



*Figure 11. Prevalence of independence in six activities of daily living (ADL) among NCCs (N=149)* 

#### (II) Physical exercise and daily activities

Most caregivers reported that NCCs maintained some regular exercise despite the pandemic. Up to 71.6% of NCCs exercised at least once a week, the remainder reporting a lower frequency. Most exercises were low-intensity and undertaken indoors.

*Figure 12.* demonstrates the percentage of NCCs engaged in specified activities on a weekly basis. Among the listed activities, personal outdoor activities were the activities in which most NCCs engaged (45.3%), followed by reading newspapers (24.3%) and visiting community / elderly centers (20.9%). It is noteworthy that possibly due to COVID outbreaks, most activities in which NCCs participated were indoor activities, and no activity was undertaken by more than half the sample on a weekly basis. Gaming, which often requires the company of others, was reported with an even lower frequency.



Figure 12. NCCs' weekly activities

Notes: The numbers contained within the bars indicate the frequency of occurrences for each respective category.

Corresponding with NCCs' limitation in intrinsic capacity, we found only one-fifth could undertake all basic ADLs independently; most required assistance in one or more ADLs, especially bathing. Although most caregivers reported that NCCs maintained regular exercises despite the pandemic, less than half participated in outdoor activities or personal hobbies on a weekly basis. Even fewer NCCs participated in activities requiring a higher level of dexterity, mobility, and cognition, such as housekeeping and reading newspapers, reflecting our sample's low level of functional independence. These findings illustrate that the life of NCCs in the pandemic could be monotonous but was also significantly limited by their functional capacity.

## 3.4 Social support

Fewer than half of the NCCs (40.4%) enjoyed daily or weekly social activities with family and friends (*Figure 13*). Our study also adopted three items from the Lubben Social Network Scale–6 (LSNS-6)<sup>28</sup> to evaluate NCCs' social isolation. The six items are designed to measure an individual's social network and evaluate their level of social support from family and friends. Only items assessing family support were adopted. A five-point scale was used, with higher scores indicating higher levels of social support. Nearly two in five NCCs (38.2%) experienced social isolation, that is having contact with fewer than two relatives or friends within a month.

*Table 4* illustrate the distribution of responses to each item.



Figure 13. Frequencies of NCCs' social activities with family and friends (N = 148)

Notes: The numbers contained within the bars indicate the frequency of occurrences for each respective category.

Table 4. I	Distribution	of responses t	o each item	related to	NCCs	' social	network
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Items	N (%)					
	0	1	2	3	4	5
	None	One	Two	Three	Five	Nine
				or	thru	or
				four	eight	more
How many relatives do the older adult see or	3	9	13	39	44	40
hear from at least once a month?	(2.0)	(6.0)	(8.8)	(26.3)	(29.7)	(27.0)
How many relatives do the older adult feel at ease with that you can talk about private	60 (41.1)	31 (21.2)	15 (10.3)	21 (14.4)	13 (8.9)	6 (4.1)
matters?						
How many relatives do the older adult feel close	0	25	38	47	28	8
to such that you could call on them for help?	(0.0)	(17.1)	(26.0)	(32.2)	(19.2)	(5.5)

## 3.5 Caregiver-rated multidimensional well-being

## (I) Caregiver-rated physical health

The study used three items asking caregivers to rate their NCC's current health. First, they were asked to give an overall rating of their NCC's current health. About a quarter (25.2%) of the caregivers rated their NCC's current health as 'poor', while a relatively small proportion (2.0%) perceived their NCCs to have 'very poor' health. Most caregivers (40.4%) perceived their NCC's current health as 'fair'. About one-third (32.4%) rated their NCC as in 'good' or 'very good' health.



## Figure 14. Caregivers' rating of NCCs' current health status (N = 151)

In the second item, caregivers were asked to compare their NCC's health with their health a year previously. Slightly over half of the caregivers (58.0%) perceived their NCC's health as slightly worsened, while about one in five (20.0%) perceived their NCC's health as more or less the same as the previous year. Only 8.0% of caregivers perceived an improvement in their NCC's health.



Figure 15. Caregivers' rating of NCCs' health compared to the previous year (N = 150)

The third item asked caregivers to compare their NCC's health with that of an older adult of similar age. About half of the caregivers (46.0%) rated their NCC's health as 'better', while about one-third (34.0%) rated their NCC's health status as 'much better' than their contemporaries. No caregiver rated their NCC's health as 'much worse' than that of older adults of a similar age.

Figure 16. Caregivers' rating of NCC's current health status of NCCs compared to other older adults of a similar age (N = 150)



*Table 5* provides the mean and standard deviations of these three items. Most caregivers rated their NCC's current health around the mid-point of the scale. Of note, caregiver-rated health was more positive when caregivers were asked to compare the health of their NCC to that of contemporaries. However, when asked to compare their NCC's current health with their health a year previously, caregivers' ratings tended to be less optimistic.

Table 5. Mean and standard deviations of items related to NCCs' current health (N=150)

Item (Higher score, poorer health)	Mean (SD)
How would you describe NCCs' current health?	2.90 (0.92)
Compared with a year ago, how would you describe the health status of NCCs?	3.77 (0.80)
Compared with other older adults of the same age, how would you	1.91 (0.82)
describe the health status of NCCs?	

## (II) Caregiver-rated emotional and social well-being, general evaluation of NCCs' life

Most caregivers perceived their NCC's emotional well-being as 'fair' (42.9%). An almost equal proportion of caregivers (42.2%) rated their NCC's emotional well-being as 'good' or 'very good' (*Figure 17*).

## Figure 17. Caregivers' rating of NCC's perceived emotional well-being (N=147)



Over half of the caregivers rated their NCC's social well-being as 'very poor' (23.0%) or 'poor' (31.1%). About a quarter (27.7%) rated their NCC's social life as 'fair', and less than one-fifth (18.2%) regarded their NCC's social well-being as 'good' or 'very good' (*Figure 18*).



Figure 18. Caregivers' rating of NCCs' perceived social well-being (N=148)

When it comes to a general evaluation of NCCs' life, over half of the caregivers perceived their NCCs as having a fulfilling life (58.5%). Slightly more than one-third (37.4%) rated their NCC's life as overall 'fair', and only a minority viewed their NCC's life as unfulfilling.



## Figure 19. General evaluation of NCCs' life (N=147)

*Table 6* provides the mean and standard deviations of caregivers' ratings of NCCs' emotional and social well-being, and their overall evaluation of their NCC's life. With higher scores referring to poorer ratings, it was unsurprising that social well-being was rated more poorly than emotional well-being and overall life, possibly due to the pandemic-related social restrictions.

Table 6. Mean and standard deviations of caregivers' ratings of NCCs' emotional and social well-being and overall evaluation of NCCs' life

Item (Higher score, poorer well-being)	Mean (SD)
How would you describe the current emotional health of NCCs?	2.71 (0.78)
How would you describe the current social life of NCCs?	3.56 (1.09)
How would you describe NCCs' entire life?	2.39 (0.85)

Regarding NCCs' physical health, caregivers tended to provide fair to positive evaluations when asked to compare it with the health of their NCC's contemporaries, but also mostly reported an observable decline compared to their health the previous year. Likewise, a poorer evaluation was also observed with NCCs' social well-being, compared to their emotional well-being and a general evaluation of their lives. Both appeared to reveal the effects of sheltering-in-place due to the COVID-19 pandemic, which severely impacted NCCs' physical and social well-being, despite all of them receiving care from their relatives.

## 3.6 Comparisons with the HKCS1 (2011) cohort

As all NCCs in the HKCS2 received care in the community from a family member, we compared the health statuses of NCCs of HKCS2 (2021/22) with those of a sub-sample of 77 community-dwelling NCCs from HKCS1 (2011) who were living with a family member.

## (I) Physical health

The number of chronic illnesses (out of a list of 22 illnesses evaluated in both HKCS1 and HKCS2) was comparable between two cohorts of community-dwelling NCCs. In terms of frailty, the proportion of frail NCCs had almost doubled, while the proportion of those described as 'robust' fell from 26.0% to just 5.7%. Regarding hospitalization and medication, fewer NCCs had been hospitalized in the past two years; however, about a quarter were still taking five or more prescription medications daily. While the proportion of significant weight loss (3kg or more in the previous six months) and loss of appetite remained more or less the same, indicating a similar level of (mal)nutrition, NCCs' mobility had significantly decreased. However, the incidence of falls in the previous six months remained similar across the two cohorts. *Table 7* provides a comparison of these two cohorts of the abovementioned indicators of physical health.

	HKCS1 (2011)	HKCS2 (2021/22)
No. of chronic illnesses	2.5 (1.6)	2.9 (1.6)
CCI	5.4 (1.4)	5.0 (1.1)
Frailty		
Frail	23.4%	55.3%
Pre-frail	50.6%	39.0%
Robust	26.0%	5.7%
Hospitalization in past 2	62.3%	42.4%
years		
Polypharmacy (using 5 or	23.6%	26.5%
more prescriptions daily)		
Weight loss	19.7%	17.6%
Loss of appetite	13.2%	14.6%
Independent indoor transfer	88.7%	48.3%
Independent stair-climbing	69.3%	13.2%
Independent walking 400m	41.5%	15.9%
Fall in past six months	17.9%	19.5%

## (II) Functional health

There is significantly decreased functional health in community-dwelling NCCs across the two cohorts. Over 70% of the 77 community-dwelling NCCs from HKCS1 could complete all basic activities of daily living (BADL) independently. However, the percentages fell to between 46.0% among 60.0% for HKCS2 NCCs. In HKCS1, the tasks in which NCCs demonstrated the most independence were toileting (90.9%) and eating (94.8%), while those in HKCS2 NCCs were continence (65.3%) and toileting (60.0%). In general, only 23.5% of the HKCS2 NCCs were fully independent in the six BADL, compared to up to 64.5% in HKCS1.





## (III) Psychological well-being and cognition

The proportion of NCCs often experiencing fear, anxiety and loneliness increased from 8.1% to more than a quarter. There was also a significant increase in the number of NCCs displaying self-perceived uselessness and a slight drop in the proportion of NCCs showing a similar level of happiness as when they were young. In terms of cognition, the proportion of NCCs receiving a diagnosis of dementia increased from 6.5% to 37.7%.

Notes: The numbers contained within the bars indicate the frequency of occurrences for each respective category.





## (IV) Social well-being and daily activities

Although HKCS2 caregivers reported only a slightly smaller proportion of NCCs engaging in regular exercise compared to the HKCS1 cohort (71.6% vs. 75.3%), it is conceivable that with the COVID-19 social restrictions, most of these physical exercises were conducted indoors. Accordingly, the proportion of NCCs engaging in weekly personal outdoor activities, attending elderly centers, taking part in social gatherings, undertaking activities requiring dexterity, mobility, and intact cognition such as household chores and reading, also fell.





Notes: The numbers contained within the bars indicate the frequency of occurrences for each respective category.

HKCS1 and HKCS2 followed different data collection protocols; the former relied on NCCs' self-reports through face-to-face interviews, whereas the latter employed telephone interviews with the primary caregivers. However, previous research shows that caregivers can provide accurate depictions of their NCCs' health status as long as they provide an adequate volume of care<sup>38,39,40</sup>. As expected, as a result of the pandemic-related social restrictions, HKCS2 NCCs exhibited poorer physical, functional, psychological and social well-being than their HKCS1 counterparts. Notably, despite the similar level of multimorbidity, fall risk, polypharmacy and nutritional status, and an even lower rate of hospitalization, mobility, emotional well-being, independence of daily life tasks and weekly activities decreased sharply. Notwithstanding the higher public awareness of dementia potentially leading to the inflated percentages of NCCs with such a diagnosis, the COVID pandemic may have been costly to the multidimensional well-being of these very older individuals, resulting in the abovementioned observable differences between the two cohorts.

<sup>&</sup>lt;sup>38</sup> Miller, L. S., Brown, C. L., Mitchell, M. B., Williamson, G. M. (2013). Activities of daily living are associated with older adult cognitive status: caregiver versus self-reports. *Journal of Applied Gerontology, 32*(1), 3-30. doi:10.1177/0733464811405495.

<sup>&</sup>lt;sup>39</sup> Phung, T. K. T., Siersma, V., Vogel, A., Waldorff, F. B., & Waldemar, G. (2018). Self-rated versus caregiverrated health for patients with mild dementia as predictors of patient mortality. *The American Journal of Geriatric Psychiatry*, 26(3), 375–385. https://doi.org/10.1016/j.jagp.2017.06.005.

<sup>&</sup>lt;sup>40</sup> Hongisto, K., Väätäinen, S., Martikainen, J., Hallikainen, I., Välimäki, T., Hartikainen, S., Suhonen, J., & Koivisto, A. M. (2015). Self-rated and caregiver-rated quality of life in alzheimer disease with a focus on evolving patient ability to respond to questionnaires: 5-year prospective ALSOVA cohort study. *The American Journal of Geriatric Psychiatry*, *23*(12), 1280–1289. https://doi.org/10.1016/j.jagp.2015.07.002.

## **CHAPTER 4 CHARACTERISTICS OF CAREGIVERS**

## 4.1 Demographic characteristics

This study collected data from 151 caregivers, 75.5% of whom were female. The age of caregivers ranged from 24 to 92; the average age of caregivers was 65.4 (SD=10.6), with over 57.6% being 65 or older. Half of the caregivers were married (51.0%), and most had received either senior secondary education (31.6%) or post-secondary education (30.2%). About half had no religious affiliation (53.4%). Most had retired (70.2%), and caregivers' median monthly household income was less than HKD10,000.

Over 80% of the caregivers were adult children of the NCCs (sons: 22.5%; daughters: 58.3%). About half (56.3%) lived in the same accommodation as their NCC. Where the caregiver and NCC did not live together, the average traveling time between the caregiver's and the NCC's home was 14 minutes, ranging from 0 to 180 minutes.

About half of the caregivers (51.7%) reported no financial pressure, 36.4% reported mild pressure, and 2.7% reported very stressful financial circumstances. Around 20% needed to support another family member besides the NCC (e.g., children). *Table 8* summarizes caregivers' socio-demographic characteristics.

	Caregivers	
	N (%)	
Gender (N=151)		
Male	37 (24.5%)	
Female	114 (75.5%)	
Marital Status (N=151)		
Married	77 (51.0%)	
Bereaved	18 (11.9%)	
Divorced	8 (5.3%)	
Never married	48 (31.8%)	
Educational Level (N=149, Miss	ing=2)	
No formal education	12 (8.1%)	
Primary education	29 (19.5%)	
Junior secondary education	16 (10.8%)	
Senior secondary education	47 (31.6%)	
Post-secondary/Tertiary	45 (30.2%)	
education		
Religions (N=148, Missing=3)		
Christianity	26 (17.6%)	
Catholic	13 (8.8%)	
Buddhism	14 (9.5%)	
Taoism	2 (1.4%)	
Folk Religion	14 (9.5%)	

 Table 8. Caregivers' key socio-demographic characteristics

No	79 (53.4%)
Relationship with NCCs (N=151	)
Spouse	6 (4.0%)
Son	34 (22.5%)
Daughter	88 (58.3%)
Daughter-in-law	9 (6.0%)
Granddaughter	7 (4.6%)
Granddaughter-in-law	1 (0.7%)
Nephew	1 (0.7%)
Niece	3 (2.0%)
Others	2 (1.3%)
Living with NCCs (N=151)	
Yes	85 (56.3%)
No	66 (43.7%)
Occupations (N=151)	
Full-time	19 (12.6%)
Part-time	17 (11.3%)
Unemployed	5 (3.3%)
Retired	106 (70.2%)
House Maker	4 (2.6%)
Financial stress (N=151)	
No or minimum	78 (51.7%)
Mild	55 (36.4%)
Moderate	14 (9.3%)
Very stressful	3 (2.0%)
Extremely Stressful	1 (0.7%)
Other family members that careg	ivers are currently supporting (N=148, Missing=3)
Toddlers	9 (6.1%)
Children	7 (4.7%)
Youngsters	2 (1.4%)
Elderly	10 (6.8%)
Others	1 (0.7%)
None	119 (80.4%)

Figure 23. Age groups of caregivers (N=151)



## 4.2 Physical and mental health

## (I) Physical health

About half (45.6%) of the caregivers regarded their health as 'good' or 'very good', while another 44.2% regarded their health as 'fair' (Figure 24). Most caregivers had not experienced a fall in the previous six months (91.2%), nor a hospitalization in the previous two years (84.5%).

## Figure 24. Caregivers' self-rated health (N=148)



*Figure 25* displays the number of chronic illnesses experienced by caregivers. The largest proportion of caregivers (48.3%) had no chronic illness, while 45.5% had one to two chronic illnesses. The most prevalent chronic illnesses among caregivers were high blood pressure (25.0%), cataracts (11.5%), osteoporosis (8.1%), and diabetes (8.1%).



Figure 25. Number of chronic illnesses among caregivers (N=145)

#### (II) Mental health

As with NCCs, we adopted the four-item patient health questionnaire (PHQ-4) to assess caregivers' mental health status based on caregivers' own ratings. The total mean score of PHQ-4 among the caregivers was 1.51 (SD = 2.314). Using a cut-off score of  $\geq$ 3 for the first two questions, only 8.1% had anxiety at a level meriting clinical attention. Applying a cut-off score  $\geq$ 3 for the last two questions, about 4.1% had depression symptoms potentially warranting clinical support<sup>27</sup>.



Figure 26. Distribution of caregivers' scores for the four-item patient health questionnaire among caregivers (N=148)

Adopting the 6-item Lubben Social Network Scale<sup>41</sup>, using a cut-off score of =<11, about half of the caregivers (52.4%) had contact with fewer than two relatives or friends within a month and are regarded as experiencing social isolation.

<sup>&</sup>lt;sup>41</sup> Lubben, J., Blozik, E., Gillmann, G., Iliffe, S., von Renteln Kruse, W., Beck, J. C., & Stuck, A. E. (2006). Performance of an abbreviated version of the Lubben Social Network Scale among three European communitydwelling older adult populations. The Gerontologist, 46(4), 503-513.



*Figure 27. Score distribution of 6-item Lubben Social Network Scale among caregivers* (*N*=147)

Although most caregivers were older adults themselves, it was encouraging to learn that many maintained good self-rated health, and the incidence of falls and hospitalization remained at a low level. The proportion of caregivers exhibiting levels of anxiety and depression warranting clinical attention was also low and comparable to those of the general population, despite the high prevalence of social isolation. In the open-ended questions, many caregivers remarked that being a caregiver for their NCC had motivated them to maintain good health and remain resilient. However, the high level of social isolation experienced by caregivers may hint at their reliance on a close social network for assistance and maintaining their well-being.

#### 4.3 Caregiver burden and gains

#### (I) Caregiver burden

The study utilized the four-item Zarit Burden Interview (ZBI-4) to evaluate caregivers' burden. This assessment has been employed in studies targeting caregivers of individuals with diverse conditions like dementia and chronic illnesses. Each question in the ZBI-4 is rated on a 5-point Likert scale ranging from 0 (never) to 4 (nearly always), with a maximum total score of 16. Elevated scores signify an increased level of caregiver burden. Using a cut-off score of 8, only 18.2% of the caregivers were categorized as experiencing a high level of caregiver burden<sup>29,42,43</sup>. The mean score of the ZBI-4 scale was 4.73 (SD = 4.12).

<sup>&</sup>lt;sup>42</sup> Center for Healthy Living. (2011). Zarit Burden Interview: Assessing caregiver burden. Available from: https://wai.wisc.edu/wp-content/uploads/sites/1129/2021/11/Zarit-Caregiver-Burden-Assessment-Instruments.pdf

<sup>&</sup>lt;sup>43</sup> Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *The Gerontologist, 20*(6), 649–655. https://doi.org/10.1093/geront/20.6.649

Figure 26. Distribution of Zarit 4-items Burden Interview scores (N = 148)



#### (II) Caregiver gain

In assessing the gains and the rewards experienced by caregivers of NCCs, the study adopted five items from the Positive Aspects of Caregiving (PAC) scale<sup>44,45</sup>. Each item is rated on a 5-point Likert scale ranging from 0 (never) to 4 (nearly always), with a maximum total score of 20. Higher scores represent a higher level of caregiver gains. By dividing the sample by the mid-point of the possible range of score (i.e., >=11), 41.1% of the caregivers were categorized as having a substantial amount of gain<sup>44</sup>. The mean score of the PAC scale was 8.80 (SD = 6.56).

<sup>&</sup>lt;sup>44</sup> Lou, V. W., Lau, B. H., & Cheung, K. S. (2015). Positive aspects of caregiving (PAC): Scale validation among Chinese dementia caregivers (CG). *Archives of Gerontology and Geriatrics, 60*(2), 299–306. https://doi.org/10.1016/j.archger.2014.10.019.

<sup>&</sup>lt;sup>45</sup> Tarlow, B. J., Wisniewski, S. R., Belle, S. H., Rubert, M., Ory, M. G., & Gallagher-Thompson, D. (2004). Positive aspects of caregiving: Contributions of the REACH Project to the development of new measures for Alzheimer's caregiving. *Research on Aging*, *26*(4), 429–453. https://doi.org/10.1177/0164027504264493.

Figure 27. Distribution of Positive Aspects of Caregiving (PAC) scale scores (N = 146)



Notes: The numbers contained within the bars indicate the frequency of occurrences for each respective category.

The caregiving experience is often an ambivalent one encompassing both pain and gain. While 18.2% of the caregivers reported a significant caregiver burden, over 40% reported significant gains from the caregiving experience. Based on caregivers' verbal responses, caregiver burden is often a result of their helplessness in coping with the vicissitudes of NCCs' physical and functional health (e.g., sudden hospitalization, acute illnesses) and physical and mental strains when providing round-the-clock and/or personal care. However, caregivers also reported feeling grateful for this role as they were able to repay the love of their elderly parents through taking care of them, learning about and better preparing for their own ageing, and fostering more harmonious family relationships.

## **CHAPTER 5 TECHNOLOGY AND CAREGIVING**

## 5.1 Attitudes and use of technologies

The study evaluated whether family caregivers utilized technology to care for their NCCs. Smartphone applications (86.1%) and technology for health records and measurements (84.4%) were the two types of technology used most by caregivers.

Table 9. Type of technology (N = 141) used by caregivers in caregiving

Types of technology (N = 141)	
Smartphone applications (e.g. WhatsApp, YouTube, WeChat, etc.)	96 (86.1)
Health equipment /exercise equipment	53 (37.6)
Urgent notification of products and services (e.g. motion sensors, safety	61 (44.9)
alarms)	
Health records and measurements (e.g. glucose meters, blood pressure	
monitors)	

*Table 10* demonstrates caregivers' perceptions of using technology in their caregiving role with reference to the Senior Technology Acceptance  $Model^{46}$ .

We generally witnessed positive attitudes towards using technologies in caregiving, including viewing technologies as efficacious, providing convenience and easy to use. Caregivers exhibited high self-efficacy and low anxiety in using technologies. They also reported good support from friends and family to use technologies, but perceived financial affordability remained rather low.

Table 10. Caregivers' perceptions of using technology in their caregiving (N=140)

Please recall your experiences of using technology to assist in		Low	High
caring for the elderly and decide whether you agree or not with	M (SD)	(≤5)	(≥ 5)
the following statement on a scale of	M (SD)	N(%)	
0 (completely disagree) to 10 (completely agree):			
Employing technology is an efficacious approach in	7.58	27	113
caregiving.	(2.30)	(19.3)	(80.7)
Employing technology confers convenience in one's life.	8.08	13	127
	(2.02)	(9.3)	(90.7)
You think technology is easy to use.	7.68	22	118
	(1.99)	(15.7)	(84.3)
Given a demonstration, you are capable of utilizing technology	8.09	18	122
to accomplish a task.	(1.83)	(12.9)	(87.1)
You exhibit reluctance in adopting technology due to	3.41	97	43
apprehension of committing irreversible errors.	(3.63)	(69.3)	(30.7)

<sup>&</sup>lt;sup>46</sup> Chen, K., & Chan, A. H. (2014). Gerontechnology acceptance by elderly Hong Kong Chinese: A senior technology acceptance model (STAM). *Ergonomics*, *57*(5), 635–652. https://doi.org/10.1080/00140139.2014.895855.

Your financial situation does not limit you from using		81	59
technology.	(3.66)	(57.9)	(42.1)
Your family and friends support you in using technology.	7.80	33	106
	(2.83)	(23.7)	(76.3)

## 5.2 Case studies of technology use for ageing-in-place

Following relaxation of the pandemic-control policies, the research team was able to contact two individual caregivers for an in-depth interview at the NCC's usual residence. These case studies illustrate disparate usage of technologies in family care for community-dwelling older adults. In-home assessment and gerotech recommendations were provided by JC Age@Home Gerotech Education and Rental Service.

## Case Study 1 – Smartphones and tablets to ward off loneliness

Ms Y is 96 years old and living with a domestic helper in a public estate. Ms C, her daughter aged 70, is Ms Y's primary caregiver, even though Ms Y's five sons and daughters harmoniously share the caregiving duties among themselves. Despite the pains and strains on her lower limbs that affect her gait and mobility, Ms Y is fairly healthy and independent. She can get around in her apartment with the help of an improvised wheelchair and is autonomous as regards most basic activities of daily living. However, she needs to be accompanied outdoors. Ms Y remains cognitively sound and has a cheerful personality. During the home assessment, Ms Y shared a lot about her past experiences as a staff member in a hotel laundry and accurately recalled her daughters' and sons' telephone numbers.

With such cognitive astuteness, during the pandemic, Ms Y used her smartphone to keep in touch with her family in Hong Kong and abroad. Ms C expressed that her mother is enthusiastic about learning and trying out 'new things', and she has been using a smartphone for several years after seeing her sons and daughters owning one. Ms C mentioned it was not very difficult to teach her mother to use a smartphone, thanks to her intact cognition. Initially, Ms Y used the smartphone to view photographs of family members, then advanced to playing games on her phone, using WhatsApp's video-conferencing function and enjoying Cantonese opera on YouTube channels. Sometimes, when Ms Y missed a call from her family, she would not only dial back but also initiate a FaceTime call to make sure her family knew she was well.

Besides her smartphone, Ms Y also enjoys playing mahjong on her tablet. During the pandemic, she could not enjoy as many social gatherings as previously and stayed at home most of the time. The mahjong game on her tablet became an essential means of passing the time. She mentioned that she enjoys speaking to her great-grandchildren abroad through her smartphone; the mahjong matches on the tablet kept her engaged and enabled her to forget her knee pain.

As a caregiver, Ms C highly recommends teaching even older adults of such advanced age to use a smartphone and tablet, not only to keep them company through online means, but also enhance their sense of mastery and life satisfaction through learning something new and teaching their contemporaries.

## Case Study 2 – Gerotechnologies for aging-in-place for frail older adults

Ms C is 102 years old and lives with two domestic helpers, who have been supporting Ms C for more than 20 years, in a private apartment. Mr M is Ms C's primary caregiver. Even though Mr M does not live with Ms C, he visits her several times a week. Ms C suffers from frailty and a notable degree of cognitive impairment, even though she still radiates a cheerful personality and a gentle persona. Mr M described Ms C as good natured and believed that she enjoyed such longevity because of her healthy mindset.

With her mobility problem, frailty and cognitive impairment, Ms C relies on the two domestic helpers for basic activities of daily living and has not been out of her residence for months, especially during the COVID pandemic. In her daily care, transfer and bathing are the most difficult. Mr M obtained a hoist from a friend to transfer Ms C her bed and her chair in the living room to minimize Ms C's risk of falling and the domestic helpers' risk of physical strain or injury.

Another critical issue pertains to bathing. Ms C is largely chair-bound; hence, she needs to be seated when showering. As her wheelchair cannot enter the bath-tub, the two domestic helpers can only bathe her in the toilet with her seated in her wheelchair. As the toilet floor does not have a drain to drain the bath water, when one helper helps Ms C with bathing, the other helper needs to constantly wipe the toilet floor to prevent the bath water overflowing. Not only does this renders bathing very cumbersome for the domestic helpers, this also presents additional fall risks with the wet toilet floor. The gerotech consultant advised Mr M to use a showering machine (洗頭機) that simultaneously releases fresh water and drains away used water during the cleaning process. Mr M tried the product for a week, but declined to rent it for longer because neither Ms C nor the domestic helpers could get accustomed to this new way of bathing.

As a highly educated engineer, Mr M acknowledges the benefits of gerotechnologies in supporting ageing-in-place for frail older adults and is cognizant of some of the latest developments in gerotechnological products. However, he remarked that it will take time for older adults to get accustomed to new practices, and public education targeting family caregiving on gerotechnologies will be essential.

## **CHAPTER 6 DISCUSSION AND RECOMMENDATIONS**

In the past decade, Hong Kong has witnessed a six-fold increase in the population of centenarians while experiecing only a 5% increase in its total population<sup>47</sup>.

As the oldest-old adults have become the fastest-growing cohort, it is imperative that different sectors of society understand the multidimensional needs of these older adults and their families. The Hong Kong Centenarian Study 2 (HKCS2) captured the characteristics and livelihood of older adults aged 95 or above and their family caregivers during the COVID-19 pandemic. Like the Hong Kong Centenarian Study 1 (HKCS1), conducted more than a decade previously, we found that most of these oldest members of our society suffered from multidimensional challenges, including multimorbidity, frailty, functional dependence, and social isolation. Most of these older adults were being cared for by their adult children, who are also older adults. Unlike the previous study, HKCS2 focused on community-dwelling NCCs supported by family caregivers. Unfortunately, despite their longevity and family support, these NCCs fared worse regarding their physical, functional, cognitive and psychosocial well-being than those of the previous cohort who were also living in the community with their families. We speculated that the COVID-19 pandemic may have adversely impacted our participants' health. Hence, post-pandemic multi-pronged support to these families will be crucial for halting the downward cascade of functional and health decline among these NCCs, and relieving their caregivers' burden.

#### International comparisons on centenarians' health

Centenarian studies have been conducted in different parts of the world, including China, Japan, Portugal, Spain, Sweden, the United States, etc. These studies often feature physical health, disease burdens, functional independence, cognition and sensory impairment, while psychosocial indicators such as depression and social isolation are less commonly investigated. Nonetheless, we attempted to interpret the findings of HKCS2 with reference to those from other centenarian studies along the dimensions of physical health, functional health, cognition, sensory problems and psychosocial well-being.

With respect to physical health, most studies found only a minority of centenarians free from any chronic diseases. The Chinese Longitudinal Healthy Longevity Study (CLHLS)<sup>48</sup> found 32.1% of centenarians had no reported major chronic disease, while the corresponding percentage was only 6% in a Spanish centenarian sample<sup>49</sup>. Vetreno et al. (2021)<sup>50</sup> found that only 5% of their centenarian sample had fewer than two chronic diseases, and the average number of chronic diseases was 3.6. These are similar to the HKCS2 findings where close to 75% of the NCCs had three or more chronic diseases. The most commonly reported chronic

https://www.thestandard.com.hk/section-news/section/11/243540/HK's-hearty-longevity-edge.

<sup>&</sup>lt;sup>47</sup> Lee, J. (2022, July 12). HK's hearty longevity edge. *The Standard*. Available from:

<sup>&</sup>lt;sup>48</sup> Lu, S., Shogo, I., Feng, Q., & Yeung, W. J. (2022). Are centenarians successful agers? Evidence from China. *Journal of the American Geriatrics Society*, https://doi.org/10.1111/jgs.18200.

<sup>&</sup>lt;sup>49</sup> Gimeno-Miguel, A., Clerencia-Sierra, M., Ioakeim, I., Poblador-Plou, B., Aza-Pascual-Salcedo, M., González-Rubio, F., Rodríguez Herrero, R., & Prados-Torres, A. (2019). Health of Spanish centenarians: a cross-sectional study based on electronic health records. *BMC Geriatrics*, *19*(1), 226–226. https://doi.org/10.1186/s12877-019-1235-7.

<sup>&</sup>lt;sup>50</sup> Vetrano, D. L., Grande, G., Marengoni, A., Calderón-Larrañaga, A., & Rizzuto, D. (2021). Health trajectories in Swedish centenarians. *The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences*, 76(1), 157–163. https://doi.org/10.1093/gerona/glaa152.

conditions are cardiovascular diseases, hypertension, degenerative joint diseases, and dementia<sup>48, 49, 50</sup>, similar to HKCS2. The Oporto Centenarian Study in Portugal also measured frailty with the phenotype approach and reported 51.6% and 42.9% of their centenarian sample as frail and pre-frail, respectively, similar to that revealed in HKCS2 (55.3% & 39.0%). In Gimeno-Miguel and colleagues' Spanish study<sup>49</sup>, 50% of their centenarians took five or more prescription medicines per day (i.e., polypharmacy), while the condition was only reported by 26.5% of our sample.

For functional health, intact functioning in activities of daily living (ADL) was found among 65% and 55% of Chinese and Spanish centenarians, respectively<sup>48,49</sup>. However, only 23.5% of NCCs in Hong Kong were independent on all ADL, which is comparable to the findings from the Tokyo Centenarian Study<sup>51,52</sup> (TCS; Perfect Barthel index (=100): 5.9% in women, 18.5% in men; independent ADL (=80-99): 13.5% in women and 24.6% in men).

For cognition, 37.7% of our sample had a diagnosis of dementia, whereas over 70% of caregivers reported an observable decline in their NCC's cognitive capacity in the previous year. The CLHLS found intact cognition among 71.3% of Chinese centenarians<sup>48</sup>, while just 39% of the Swedish centenarians reported in Ventrano et al. (2021)<sup>50</sup> preserved good cognitive capacity. In the TCS, 41.6% and 67.4% of male and female centenarians, respectively, suffered from any degree of dementia <sup>51,52</sup>.

For sensory impairment, 45.7% and 59.6% reported vision and hearing impairmenst despite having spectacles or hearing aids. In the Georgia Centenarian Study, 56.7% and 56.9% of centenarians reported vision and hearing problems, respectively, whereas the corresponding ratios were up to 63.6% and 72.8% in the TCS<sup>53</sup>.

For psychosocial well-being, 33.8% of the centenarians in the CLHLS<sup>48</sup>, and 72% of the New York centenarians in the Fordham Centenarian Study (FCS) reported no or minimal depressive symptoms, while the percentage of Hong Kong NCCs scoring 0 on the depressive subscale of Patient Health Questionnaire-4 (PHQ-4) was 43.7%. 35.2% of the Oporto centenarians reported depression<sup>54</sup>, whereas 28.9% of our caregivers said their NCC exhibited depressive symptoms warranting clinical attention. 38.2% of our NCC sample experienced social isolation, while up to 51.1% of the centenarians in the FCS<sup>55</sup> did so.

<sup>&</sup>lt;sup>51</sup> Arai, Y., Inagaki, H., Takayama, M., Abe, Y., Saito, Y., Takebayashi, T., Gondo, Y., & Hirose, N. (2014). Physical independence and mortality at the extreme limit of life span: Supercentenarians study in Japan. *The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences, 69*(4), 486–494. https://doi.org/10.1093/gerona/glt146.

<sup>&</sup>lt;sup>52</sup> Arai, Y., Sasaki, T., & Hirose, N. (2017). Demographic, phenotypic, and genetic characteristics of centenarians in Okinawa and Honshu, Japan: Part 2 Honshu, Japan. *Mechanisms of Ageing and Development, 165*(Pt B), 80–85. https://doi.org/10.1016/j.mad.2017.02.005.

<sup>&</sup>lt;sup>53</sup> Martin, P., Gondo, Y., Arai, Y., Ishioka, Y., Woodard, J. L., Poon, L. W., & Hirose, N. (2018). Physical, sensory, and cognitive functioning among centenarians: a comparison between the Tokyo and Georgia centenarian studies. *Quality of Life Research : An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, 27(11), 3037–3046. https://doi.org/10.1007/s11136-018-1943-z.

<sup>&</sup>lt;sup>54</sup> Ribeiro, O., Duarte, N., Teixeira, L., & Paúl, C. (2018). Frailty and depression in centenarians. *International psychogeriatrics*, *30*(1), 115-124.

<sup>&</sup>lt;sup>55</sup> Zaccaria, D., Cavalli, S., Masotti, B., Gomes Da Rocha, C., von Gunten, A., & Jopp, D. S. (2022). Social Isolation and Loneliness among Near-Centenarians and Centenarians: Results from the Fordham Centenarian Study. *International Journal of Environmental Research and Public Health*, *19*(10), 5940. https://doi.org/10.3390/ijerph19105940

In terms of physical health, functional independence, cognition, sensory functions, and psychosocial well-being, Hong Kong centenarians tended to perform on a par with their international counterparts. Although different studies may operationalize indicators differently, health and functional declines among centenarians appear to be pancultural.

## Caregiving for NCCs in the community

Over 80% of our caregivers were adult children of the NCCs, with the majority being daughters. These adult children caregivers are often young-olds themselves. Our interviews revealed the unique challenges faced by these caregivers, including physical and mental exhaustion due to their own ageing and the escalating personal care needs of their often-frail older parents. The caregiving experience is filled with both pains and gains. Caregivers regarded the burdensome role as a repayment for the love of their spouse or parents and a unique window to 'preview' what ageing will be like when they hit their nineties or an even older age. This resonates with the findings from the limited body of studies on caregiving for centenarians<sup>19,20</sup>.

According to a report from the Census and Statistics Department, over 73% of local older adults owned a smartphone<sup>56</sup>. The prevalence of smartphones could be germane to the mostly positive attitudes among our caregivers regarding the use of technologies in providing care for their older adults at home. Most caregivers found technologies efficacious and convenient aids for ageing-in-place. However, most technologies they were using were rather 'basic' (e.g., smartphone apps, electronic blood-pressure-meters, remote cameras). The interviews revealed that caregivers do not think technologies can replace human effort in providing care, especially caregivers' patience and passion for providing quality care for their loved ones. However, they were generally optimistic about the increasing participation of technologies in future elderly care.

## Strengths and limitations

Following the multidisciplinary perspective of HKCS1, this study adopted a biopsychosocial approach to explore the well-being and challenges of NCCs and their family caregivers in Hong Kong. We consider that this study possibly exposed the best-case scenario for the oldest-old cohorts of Hong Kong as our participants were all community-dwelling older adults supported by their families. Hence, they were likely to fare better in terms of physical health compared to their counterparts residing in care and attention homes and receive better social support than those living alone. Phone interviews with caregivers provided us with unique insights about community care for these oldest-old adults and how technologies may foster the well-being of both generations of older adults (i.e., young-old adult children and oldest-old parents). Recruiting a geographically representative sample from 31 non-governmental organizations and elderly service units enabled us to obtain a sample representing the diversity inherent among local Chinese families with community-dwelling oldest-old adults.

However, the study also suffers from several limitations. First, we did not rely on a populationbased registry for recruitment. Hence, families with no contact with local services may have been outside our reach and were not engaged in this study. The lack of access to a centralized

<sup>&</sup>lt;sup>56</sup> Census & Statistics Department. (2022). *Thematic household survey report - Report No. 69 - Personal computer and Internet penetration*.

registry prevented us from inviting all eligible families in Hong Kong to participate in the study and derive a response rate. Second, we relied on caregivers' knowledge, observations, and impressions to ascertain NCCs' circumstances. Hence, some indicators, especially those related to the NCCs' emotional well-being, could be inferences by the caregivers based on the NCCs' verbal and non-verbal expressions and could be coloured by caregivers' own emotional state<sup>57, 58, 59</sup> as well. However, previous studies found that caregivers may reveal a more realistic picture of NCCs' cognition, especially with NCCs demonstrating marked cognitive decline<sup>38, 39, 40</sup>.

Also, compared to the single-time observation made by a newly-acquainted researcher, caregivers' ratings could be more accurate, as they tend to be aggregated estimates of NCCs' recent performance. Third, due to the COVID-19 pandemic, we were unable to visit participants' homes; therefore, we have neither researcher-observed nor self-rated data about NCCs' physical capabilities or their living environment. Fourth, phone interviews necessitated striking an intricate balance between the comprehensiveness and the brevity of measurements, and therefore most constructs were not measured using the full version of the validated scales.

#### **Policy recommendations**

#### (I) Gerontechnologies for ageing-in-place:

Technologies have been used to both enhance interpersonal connections for support, entertainment, and information and foster functional independence of community-dwelling older adults. For caregivers, on the one hand, technologies may help reduce physical and mental exhaustion by simplifying caregiving tasks; on the other hand, they may enhance the quality of life of their older adults and indirectly benefit their own quality of life. Based on our findings regarding NCCs' health and the caregivers' caregiving challenges, technologies including mobile devices (e.g., smartphones, tablets), anti-fall devices (e.g., rails in the bathrooms), mobility aids (e.g., electric beds, lifting hoists, bath chairs, multi-purpose wheelchairs), vital signs monitoring systems (e.g., real-time health monitoring platforms, telehealth systems) and in-home anti-wandering systems could be useful for families with NCCs. Hence, we propose the following:

1. Closing the intergenerational digital divide for mobile devices. The digital divide refers to the intergenerational gap between the younger and the older populations in terms of the infrastructure and material access, literacy and usage of information and communications technologies (ICTs), especially mobile devices such as smartphones and tablets in the post-pandemic era. Mobile devices are integral to the informational, instrumental, and social support for caregivers and older adults alike. Enabling older adults to make good use of their smartphones, tablets, and other forms of mobile devices for daily functions such as e-banking, m-health, transportation, socializing,

<sup>&</sup>lt;sup>57</sup> Black, B. S., Johnston, D., Morrison, A., Rabins, P. V., Lyketsos, C. G., & Samus, Q. M. (2012). Quality of life of community-residing persons with dementia based on self-rated and caregiver-rated measures. *Quality of Life Research*, *21*(8), 1379–1389. https://doi.org/10.1007/s11136-011-0044-z.

<sup>&</sup>lt;sup>58</sup> Sands, L. P., Ferreira, P., Stewart, A. L., Brod, M., & Yaffe, K. (2004). What explains differences between dementia patients' and their caregivers' ratings of patients' quality of life? *American Journal of Geriatric Psychiatry*, *12*(3), 272–280. https://doi.org/10.1097/00019442-200405000-00006.

<sup>&</sup>lt;sup>59</sup> Long, K., Sudha, S., & Mutran, E. J. (1998). Elder-proxy agreement concerning the functional status and medical history of the older person: The impact of caregiver burden and depressive symptomatology. *Journal of the American Geriatrics Society*, *46*(9), 1103–1111. https://doi.org/10.1111/j.1532-5415.1998.tb06648.x.

entertainment, e-shopping, etc., may support independent living and readily connect older adults to essential support and information.

- 2. Public education on gerotechnologies for ageing-in-place. Many caregivers lamented their have difficulties identifying technologies suitable to their caregiving challenges and needs. In other words, they have limited ideas about what they could and should choose and use. Public education on the options and the diversity of technologies that foster ageing-in-place will enable the public to be aware of, choose and use appropriate products.
- 3. Case management for gerotechnologies for community-dwelling older adults. In addition to knowing what products are available, a comprehensive assessment of the needs of older adults and the limitations of their living environment will facilitate a good match between products and users. Continued support and follow-up after rental or purchase will also support troubleshooting and enable smooth usage by older adults. Hence, a one-stop, streamlined case management approach encompassing education, assessment, rental or purchase, and follow-up will support successful adoption of gerotechnologies by community-dwelling older adults.
- 4. Financial support for rental or purchase of suitable gerotechnologies. Caregivers tend to perceive gerotechnologies as something unaffordable. They are also concerned about the cost-effectiveness of the technological products, especially when the health condition of their older adults deteriorates quickly toward the end of life and personal care needs escalate. This is also the time when technological products could be most helpful. Hence, a rental service paired with financial support may relieve caregivers of their concerns about cost-effectiveness.

#### (II) Caregiver support

Providing care for these exceptionally long-lived older adults is associated with multiple challenges requiring not only physical strength, mental vigilance but also expert knowledge and skills. A caregiver's burden tends to escalate with the oldest-old adult's deteriorating cognitive and self-care capacity. Hence, we propose the following:

- 1. A one-stop information hub for caregivers. As their oldest-old relative's care needs escalate, caregivers may need to navigate multiple healthcare and social care systems with information scattered around different corners of the internet. A one-stop information hub tailored to the preferences and needs of young-old caregivers is essential. This may be facilitated by generative AI that accommodates and processes natural language.
- 2. Increase access and flexibility for respite services. Many caregivers feel obliged to be on duty all the time and are trapped in their roles at the expense of their personal lives and health. Respite services offer caregivers valuable time to attend to other aspects of their personal and family lives and take care of themselves. Increasing the flexibility and access of the current respite services will increase their efficiency and effectiveness.

#### (III) Primary care for the management of chronic diseases

Efficacious prevention and management of chronic diseases are pivotal for a fast-ageing population. In this light, the HKSAR Government published the Primary Healthcare Blueprint in 2022, proposing frameworks for sustainable, district-based, family-centric health management by vertically streamlining primary healthcare with specialist and hospital-based

care, and horizontally coordinating district-based health and social services and resources through District Health Centers and other primary care institutions. Such augmented and integrated district-based primary healthcare will be essential for fostering all-rounded healthy ageing for both caregivers and older adults.

## **CHAPTER 7 CONCLUSION**

The Hong Kong Centenarian Study is founded on the idea that learning about the needs of the oldest people in our society will enable us to be more inclusive and tolerant of the diverse needs of the population at different points of the human lifespan. While the HKCS1 has set a pioneering example for oldest-old and centenarian studies in the Chinese population and in Asia, the HKCS2 has been privileged to capture what life has been like for families with NCCs during the COVID-19 pandemic. Although our findings have been less than optimistic - older adults in HKCS2 tended to fare worse in terms of their physical, functional, cognitive and psychosocial well-being than a similar sample in HKCS1, we have been impressed by the unfailing dedication and love of the family caregivers. Providing personal care for a frail older family member during the horrendous pandemic was undoubtedly onerous. Yet, no pain, no gain. When we asked caregivers what had driven their dedication to care for their ageing loved ones, they responded that it was both a noble duty and a repayment of love, intersected with a sense of mastery, achievement, and satisfaction. Facing the finitude of NCCs' lifespan, 'to see your loved one through' has been a huge motivation making this group of caregivers most eager to help, but also most vulnerable to caregiving stress. We are very grateful to the 151 caregivers who generously shared not only the hundred years of life stories on behalf of their NCCs, but also showed local and international gerontologists what it means to care 'until death tears us apart'<sup>20</sup>.

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