

Concept Paper

# Dementia and COVID-19 in Chile, New Zealand and Germany: A Research Agenda for Cross-Country Learning for Resilience in Health Care Systems

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**Citation:** Laporte Uribe, F.; Arteaga, O.; Bruchhausen, W.; Cheung, G.; Cullum, S.; Fuentes-García, A.; Miranda Castillo, C.; Kerse, N.; Kirk, R.; Muru-Lanning, M.; et al. Dementia and COVID-19 in Chile, New Zealand and Germany: A Research Agenda for Cross-Country Learning for Resilience in Health Care Systems. *Sustainability* **2021**, *13*, 10247. <https://doi.org/10.3390/su131810247>

Academic Editors: Jacqueline Broerse, Evelien de Hoop and Tjerk Jan Schuitmaker

Received: 15 May 2021

Accepted: 9 September 2021

Published: 14 September 2021

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**Abstract:** The COVID-19 pandemic has revealed existing gaps in policies, systems and services, stressing the need for concerted global action on healthy aging. Similar to the COVID-19 pandemic, dementia is a challenge for health systems on a global scale. Our hypothesis is that translational potential lies in cross-country learning by involving three high-income countries with distinct geopolitical-cultural-social systems in Latin America (Chile), the South Pacific (New Zealand) and Europe (Germany). Our vision is that such cross-country learning will lead to providing adequate, equitable and sustainable care and support for families living with dementia during a pandemic and beyond. We are proposing a vision for research that takes a multi-disciplinary, strength-based approach at the intersection of health care research, disaster research, global health research and dementia research. We present some insights in support of our hypothesis and proposed research agenda. We anticipate that this research has the potential to contribute towards strengthening and transforming health care systems in times of crises and beyond.

**Keywords:** dementia; COVID-19 pandemic; Chile; New Zealand; Germany; resilience; sustainable health care systems; disaster research; strength-based; community setting

## 1. Introducing a Hypothesis for Translational Learning of Health Systems in Response to the COVID-19 Pandemic

The COVID-19 pandemic has demonstrated “how an infectious disease can sweep the globe in weeks and, in the space of a few months, set back sustainable development by years” [1]. Globally, 185 million people have been confirmed infected, and close to 4 million people have died due to COVID-19 (as of July 2021) [2], with extreme social, political, economic and psychological consequences. The COVID-19 pandemic is further widening existing socio-economic and health disparities affecting especially those populations considered vulnerable. The Independent Panel for Pandemic Preparedness and Response has just reported that a loss of USD 22 trillion is expected in the period 2020–2025—the deepest shock to the global economy since World War II; gender-based violence support services have seen fivefold increases in demand; at the height of the second wave in 2020, 90% of schoolchildren could not attend school; and more than 100 million people have been pushed into extreme poverty [1]. The COVID-19 pandemic has revealed existing gaps in policies, systems and services, stressing the need for concerted global action on healthy aging [3]. Older people are disproportionately affected in emergency situations, and their needs in emergencies are often not addressed [3]. Mortality rates for people with dementia during the COVID-19 pandemic have been unproportionally high, at more than 25% globally [4]. While vaccination programs are being rolled out across the world, the COVID-19 pandemic is unfolding into another wave in most countries around the world. A rare exception to the spread of the pandemic in waves is New Zealand, where beyond the first outbreak, there were only very minor subsequent community transmissions, with the locations of interest going into immediate lockdown. The spread of the highly contagious Delta variant (B.1.617.2) that has been identified in 92 countries thus far [5] might be considered one reason for this current wave, in addition to the easing of regulations such as frequent testing, mask wearing, travel restrictions and bans on large crowd gatherings. In addition to social, economic and environmental challenges exacerbated by the pandemic, it has been found that 10% of COVID-19 patients are experiencing prolonged illness [6]. Additionally, the central nervous system might be affected in one out of three patients [7]. This, in turn, could substantially increase the incidence for neurodegenerative diseases including dementia [8]. The impact of COVID-19 on dementia and dementia services is likely to be attributable to different causes including the impact of lockdowns and social isolation on the physical and psychosocial health of elderly people or people living with dementia [9–11]. Additionally, neurologic manifestations associated with COVID-19 [12] could represent an additional burden for dementia services, although the long-term consequences are unknown, and more studies are needed [13]. Given these developments, the COVID-19 pandemic will likely continue to have an impact on our lives for years to come.

Prior to the COVID-19 pandemic, dementia was already a challenge for health systems on a global scale. It is estimated that, worldwide, around 50 million people have dementia, with almost 10 million new cases every year [14]. In 2015, the total global societal cost of dementia was estimated to be USD 818 billion, equivalent to 1.1% of the global gross domestic product (GDP) [14]. Historically, both disaster research and dementia research, as with most research directed at scientific insight into disordered mechanisms, have been largely deficit-oriented [15,16]. However, the human capacity to live well despite a disease is a phenomenon that can be described increasingly often with the rise in chronic illnesses and an increasingly aging population around the globe [17]. Correspondingly, psychosocial dementia research is increasingly often referring to strength-based and resilience-focused approaches as complementary perspectives to the dominant biomedical deficit-focused perspective [15]. Both in research on resilience as an outcome and in dementia research, integrative bio-psycho-social approaches are being focused on [16,18].

While the COVID-19 pandemic has exposed the vulnerability of our health care systems, particularly for people with dementia, there is a unique opportunity to learn from

both failures and innovations, and to scale up best practice examples of providing adequate, equitable and sustainable care and support for families living with dementia. A question arises, though, concerning where to look for innovations. If we want to increase personal as well as system preparedness, is it enough to describe innovation and best practice examples from around the globe assuming that they can be implemented in any other country? Should we not also ask how a certain innovation in coping with a care crisis came to life in the first place and what factors enabled (or hindered) its successful implementation in a certain region or country? If the goal is the translation of innovations into sustainable health care structures, we have to ask the following: How can we ensure that innovations are not merely considered as a reaction to a crisis but outlive a crisis and become part of routine care and structures? How can experiences encountered during a pandemic ultimately strengthen health system preparedness and resilience and, in turn, contribute towards increased resilience, both in people living with dementia and their families (informal caregivers) and in support structures? What are the commonalities and differences between the COVID-19 pandemic and the dementia crisis, and what lessons from the current pandemic can be applied to addressing the global challenge of dementia?

Tackling global challenges such as the COVID-19 pandemic or dementia requires a global perspective. We are confident that we can facilitate cross-country learning by comparing the different approaches taken to respond to dementia during the COVID-19 pandemic by three high-income countries in the South Pacific (New Zealand), in Latin America (Chile) and in Europe (Germany) representing different health care systems and policy responses to a disaster such as the COVID-19 pandemic while experiencing different (levels of) exposures to natural hazards and risks. Although exposure to and the type of hazards differ between and within countries, both Chile and New Zealand are countries that are prone to frequent and often high-magnitude geophysical and hydro-meteorological hazards (e.g., earthquakes, volcanic eruptions, floods, landslides). As such, they could be considered “geographical high-risk” countries, i.e., countries continuously prone to geophysical or meteorological and climatological hazards and risks. Germany only more recently began to experience increasing numbers of hazards and risks in relation to environmental degradation and climate change, but it does not experience significant geophysical hazards and, as such, could be considered a “geographical low-risk” country. This poses the following question: To what extent does the factor of being a “geographical low/high-risk” country have an impact on the attitude towards a pandemic and on the responsiveness of the health care system to the needs of people living with dementia and of their families or friends prior to and during a pandemic?

Each health system is unique, influenced by context and circumstances [19], and it is unlikely that the geographic location of a country alone serves as a key driver for system responsiveness in times of emergency. However, when considering the interplay of different health system descriptors such as country-specific socio-economic, political and policy factors and health system delivery and capacity factors, the inclusion of geophysical characteristics can serve as an additional analytical lens requiring multi-disciplinary perspectives.

In this paper, a vision for research is proposed that takes a multi-disciplinary, strength-based approach at the intersection of health care research, disaster research, global health research and dementia research. Following the introduction of our hypothesis, first, we will elaborate on the reasoning for this hypothesis and provide an overview of Chile, New Zealand and Germany in order to derive our research objectives and research questions. Second, we will present methodical and methodological considerations with regard to our research objectives. Last, we will provide some insights in support of our hypothesis and proposed research agenda, including recent developments in these countries with regard to the COVID-19 pandemic and dementia.

The hypothesis is that translational potential lies in cross-country learning by involving three high-income countries with distinct geo-political-cultural-social systems in Latin America (Chile), in the South Pacific (New Zealand) and in Europe (Germany).

Our vision is that such cross-country learning will lead to providing adequate, equitable and sustainable care and support for families living with dementia during a pandemic and beyond.

By identifying facilitators and barriers of coping with the COVID-19 pandemic and addressing dementia prior to and during this emergency in Chile, New Zealand and Germany, three countries representing different health care systems and experiencing different (levels of) exposures to natural hazards and risks, we will be able to identify structural, contextual and conceptual factors that contribute towards more equitable, resilient and sustainable health care systems. This translational potential refers to, first, the ability to cope with geographical risk and the applicability of such knowledge/experience/attitude to a pandemic; second, the ability to respond to a pandemic as a challenge for the entire health care system, and the applicability of findings to the specific context of dementia care; and third, the applicability of findings in relation to a crisis to other pandemics and times without crises.

## **2. Developing an Agenda for Cross-Country Learning for Resilience in Health Systems in Response to the COVID-19 Pandemic**

The COVID-19 pandemic has proven that “the world has been gravely under-prepared for large outbreaks of emerging infectious diseases” [20]. Critical gaps in global preparedness have been exposed [21], and the need to improve the resilience of health and care systems worldwide has become clear [22]. Pandemics are becoming more frequent as they have links to ecological disruption [23]. The main reasons for the increasing pandemic threat in the 21st century are a rapidly growing and mobile world population; urbanization trends; industrialized food production in global value chains; and the development of global transport networks acting as vectors in the spread of pathogens [24]. Expectedly, the international debate on the pandemic frequently touches on concepts that encompass the interconnectedness of human, animal and environmental health, i.e., One Health or Planetary Health [25], providing a holistic understanding of health that is not limited by structural, national or disciplinary boundaries. With the COVID-19 pandemic exacerbating inequalities and demonstrating the interconnectedness of social, economic, environmental and political factors in society, we need a shift in paradigm in building resilient and equitable societies [1,26]. However, establishing how to govern health system transformation in such a way that our health systems become more resilient to future pandemics and times without crises is a considerable challenge.

### *2.1. Resilience of Health Care Systems*

The resilience of a health care system can be defined as the capacity to absorb, respond and adapt to shocks and structural changes in order to strengthen the system and reduce its vulnerability to similar events in the future [22]. Consequently, resilient and adaptive health systems are able to protect themselves and human lives from the impact of disasters and are critical to achieving good health before, during and after disasters [22]. In fact, in the case of Chile, the very origin of the National Health Service (Servicio Nacional de Salud) relates to a bill to unify and centralize services that was presented to parliament in 1941 after an uncoordinated response of health care institutions to a severe earthquake in 1939. Defining the COVID-19 pandemic as a biological disaster [27] provides us with the opportunity to apply knowledge from disaster research. However, while resilience is a core concept in disaster risk reduction, its application to health systems is relatively new [28]. Resilient health systems can be characterized by five aspects: awareness, diversity, self-regulation, integration and adaptability [29]. In the context of the COVID-19 pandemic, it has been stressed that efforts should not solely focus on absorbing unforeseen shocks, and that the resilience of health care systems also relates to the following: the continuity in health improvement, sustaining gains in systems functioning and fostering people-centeredness while delivering high-quality care [28]. Therefore, the as-

assessment of health system resilience is vital in enabling policy makers to plan for sustainable recovery and strengthen systems to better prepare and respond to current and future crises [28].

### 2.2. Sustainability of Learning Health Care Systems

The concept of sustainability in the context of dementia care is still fairly new relating, for example, to intervention sustainability [30] or demographic sustainability [31]. Applying questions of sustainable system development in dementia against the backdrop of a pandemic presents a novel approach. Sustainability is increasingly conceptualized as a dynamic construct that allows for adaptation and capacity building in response to new or changing populations, evidence, policies or other contextual influences [32]. Only recently have dementia care researchers begun to examine sustainability across whole systems, communities, cities or countries [32]. Pandemic preparedness and response have to function at national, regional and global levels, across different sectors of social and economic life, and including government, business and community [1]. The goal of translating (pandemic) innovations into sustainable health care structures and systems calls precisely for such a dynamic understanding of sustainability, whereby the evolution of interventions is a prerequisite for constant quality improvement and a learning health care system [33].

There has been a long-standing interest in cross-country comparison of health systems and policies amongst policy makers [34]. The rationale for such a comparison in our proposed research can be best described as a multi-directional learning approach whereby we are seeking “to understand processes and developments in one group of countries to inform policy learning in another” [34].

### 2.3. Inequity in Dementia Care before and during the COVID-19 Pandemic

People with disabilities (including those with dementia) are at increased risk in emergency and disaster situations including inaccessible information, exclusion, disruption of health services, narrower margin of health, breakdown of social support networks and physical barriers [35]. The severity and mortality of COVID-19 worsen with increasing age and pre-existing conditions such as diabetes and hypertensive diseases [36,37]. Reasons for the increased infection and mortality rates for people with dementia might include socio-economic determinants, behavioral factors, lifestyle such as living in a residential care setting, the cognitive difficulties associated with dementia and comorbidities [38]. Emerging evidence describes the effects of lockdown during the COVID-19 pandemic on people with dementia living in the community. One study conducted in three South American countries (including in Chile) found a significant decline in memory function (among 53% of people with dementia) as well as increased levels of sadness (31%) and anxiety (37%), with family caregivers feeling more tired and overwhelmed [11]. Therefore, those living with dementia are considered amongst the most vulnerable [3].

Fairness and equity are important values in service provision [39]. The social determinants of health (e.g., income, education, living conditions) have an important influence on health inequities—the unfair and avoidable or remediable differences in health among population groups defined socially, economically, demographically or geographically [40]. In the context of dementia care research, equity has been considered as the absence of systematic discrepancies in access to care services [41]. Data on how countries and stakeholders have been reacting to the pandemic with regard to continuing care and support for people living with dementia in the community are largely missing. Furthermore, even prior to COVID-19, accessing and utilizing care has not been equal, with the pandemic potentially further widening inequalities [42]. This might be especially true for health care systems of emerging economies where support structures are mostly privately organized and funded or are just starting to be implemented at a policy level, e.g., in Chile. Across LACs, only 1% of the population over the age of 60 years receives governmental support for long-term care, and only the wealthiest families can afford private long-term

care [43]. With an expected poverty increase, most social determinants of health will worsen, resulting in increasing inequalities among those with dementia across LACs [44]. However, those countries have been largely underrepresented in research, even though they show some of the fastest growing rates in the incidence and prevalence of dementia worldwide [36].

The relevance of our proposed research becomes even more apparent under “the Convention on the Rights of Persons with Disabilities”. It states that all necessary measures have to be taken to ensure the protection and safety of persons with disabilities in risk situations, including the occurrence of disasters (Article 11), by promoting international collaborations in partnership with regional organizations and civil society (in particular, organizations of persons with disabilities) to support national efforts in ensuring the objectives of the convention (Article 32) [45].

#### 2.4. Overview of the Three Chosen Countries: Chile, New Zealand and Germany

The following provides a first brief overview of the socio-economic, geophysical, geo-political and health system-related characteristics of Chile, New Zealand and Germany (Table 1).

**Table 1.** Overview of socio-economic, geophysical, geo-political and health system-related characteristics of Chile, New Zealand and Germany.

Characteristics	Chile	New Zealand	Germany
Socio-economic aspects	one of Latin America’s fastest-growing economies in recent decades, enabling the country to significantly reduce poverty; however, more than 30% of the population is economically vulnerable, and income inequality remains high [46]	economic growth is stable and well-being is generally high, but the income distribution is more unequal than the OECD average; “education, health and housing outcomes vary strongly by socio-economic background and ethnicity — Māori and Pasifika tend to fare worse” [47]	highly industrialized, densely populated, high-income country; robust economic growth and high well-being [48]
Geophysical, geo-political location	isolated location (Andes as a natural barrier)	isolated geographic location, island	Western European country, having a (land-)border with 9 countries
Hazards	frequent and often high-magnitude geophysical (earthquakes, tsunamis, volcanoes, landslides), climatological and meteorological (especially draughts during the last decade in the northern and central parts of the country, ENSO (ENSO: El Niño Southern Oscillation) events) hazards with the potential to create disasters	frequent and often high-magnitude geophysical hazards (earthquakes, tsunamis, landslides, volcanoes) with the potential to create disasters, no frequent meteorological hazards	no frequent geophysical and moderate meteorological hazards, but increasing hazards related to heat stress
Political stability	politically rather unstable (ongoing political protests,	politically stable (re-election of J. Ardern as prime minister in October 2020)	politically stable

	referendum for a new constitution passed on 25 October 2020)	
Health system	dual health care system, public covers 78% of the population, high out-of-pocket expenditures (35,1%) [49]; recently, the Explicit Guarantees System included Alzheimer disease and other dementias; health care system “robust” but also revealing high “levels of inequity” [50]	the health care system is administered through several autonomous bodies and associations [51], 12.3% out-of-pocket expenses [49]; universal long-term care insurance also for the older population covering home- and community-based services as well as institutional services
National dementia strategy	National Plan for Dementia launched in 2017 [52]	New Zealand Framework for Dementia Care published in 2013 [53]; the National Dementia Plan 2020–25 has not been implemented by government yet [54] “Alliance for People with Dementia” since 2012 followed by the National Dementia Strategy launched in 2020 [55]

### 2.5. Contextual Background of the COVID-19 Pandemic in Chile, New Zealand and Germany

Table 2 provides an overview of confirmed COVID-19 cases, the number of people who have died with COVID-19 and the number of people who have received at least one vaccination dose as of 16 March 2021 in Chile, New Zealand and Germany.

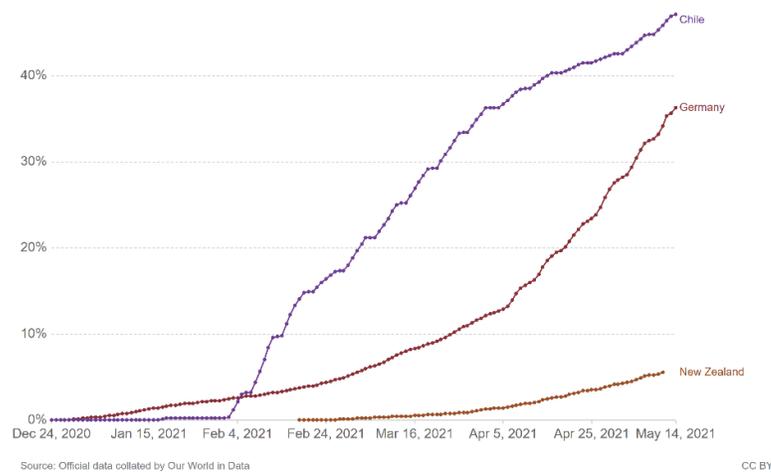
**Table 2.** Overview of COVID-19 confirmed cases, deaths and number of persons vaccinated with at least one dose as of 16 March 2021.

COVID-19	Confirmed Cases	Deaths	Persons Vaccinated with at Least One Dose
	per 100,000 <sup>1</sup>	per 100,000 <sup>1</sup>	per 100 <sup>1</sup>
Chile	4688.33	113.89	32.09
New Zealand	43.05	0.54	0.37
Germany	3074.39	87.63	9.2

Data: World Health Organization 16 March 2021 [2]; <sup>1</sup> per x population.

What can be seen from this table (Table 2) is that Chile has the most confirmed cases of COVID-19 and related deaths per 100,000 population, but Chile also has, by far, at the time of writing this paper (mid-March), the highest vaccination rate.

Figure 1 provides a graphical representation of the total number of vaccination doses administered per 100 people in the total population. Whereas Germany was the first to administer vaccinations, Chile, within a few days, took the lead in terms of vaccination rates, not just in comparison to Germany and New Zealand (who started only in mid-March to roll out COVID-19 vaccinations) but also worldwide, being, at the time of writing this article, (with the UK) third globally [2].



**Figure 1.** Total number of vaccination doses administered per 100 people in the total population [56].

Research [57] considering a number of factors (geography, political systems, population size and economic development) to determine the impact of COVID-19 outcomes around the world suggests that, indeed, there is potential for cross-country learning when looking at Chile, New Zealand and Germany (Figure 2). Differences between those countries are certainly not explained by, e.g., geography (New Zealand’s remote island location) alone. However, the graphic is a representation of data available up to 13 March 2021 and does not include vaccination rates [57]. Higher values on the y-axis in Figure 2 indicate a better overall performance in managing the COVID-19 pandemic.



**Figure 2.** Graph comparing Chile’s, New Zealand’s and Germany’s performance regarding managing the COVID-19 pandemic during the 43 weeks following the 100th confirmed COVID-19 case [57].

## 2.6. Contextual Background of Dementia in Chile, New Zealand and Germany

In 2017, the World Health Assembly (including Chile, New Zealand and Germany) endorsed the “Global action plan on the public health response to dementia 2017–2025”, which provides a set of actions to realize the vision of a world in which dementia is prevented, and people with dementia and their caregivers receive the care and support they need to live a life with meaning and dignity [58]. This vision has been challenged during the COVID-19 pandemic where care and support services have been largely disrupted or

discontinued [59]. As an urgent response to provide a continuity of care and social connectedness, care practitioners, Alzheimer and dementia support organizations and researchers around the world have turned towards information and communication technology, sharing experiences and knowledge in various databases.

### 2.6.1. Chile

#### (a) Dementia prevalence and incidence

It is estimated that, currently, about 200,000 people are living with dementia in Chile, i.e., 1% of the total population. This number is projected to increase to 600,000 (i.e., 3% of the total population) by 2050 [60].

#### (b) Dementia strategy

In 2017, the Ministry of Health launched the National Plan of Dementia [52], which proposed establishing a range of health care services from primary care to Memory Units [61]. In 2018, the plan had been implemented as a pilot in three regions across the country [62]. In 2019, a policy paper was published to raise awareness with policy makers, proposing to put dementia on their agenda and emphasizing the need to keep supporting the National Plan by implementing it nationwide [62]. Recently, Alzheimer disease and other dementias were included in the Explicit Guarantees System (Acceso Universal con Garantías Explícitas, or AUGE) [63] with capped, considerably reduced co-payments and limits on the maximum waiting time [64]. However, the need for continuous care and management by multi-disciplinary teams in the context of dementia presents funding challenges for both the public and the private sector, with the latter being for-profit in Chile [65,66].

#### (c) Current developments in research

Only very recently was a research and networking initiative set up to expand dementia research in Latin America (ReDLat), aiming at identifying the unique genetic, social and economic factors driving the presentation of frontotemporal dementia and Alzheimer disease in Latin America [67]. Over recent years, there have been a growing interest in and research output on care and costs of dementia in Chile as well as the need for cultural adaptation of existing psycho-social interventions [68–71].

#### (d) Reactions to the COVID-19 pandemic

Dementia-specific data are still missing. However, in May 2020, it was reported that nearly 80% of COVID-19 cases occurred in highly densely populated metropolitan regions, with older people (60+) having been disproportionately affected; they represented only 15.7% of the cases, but 48% of hospitalizations and 89.6% of all deaths [72]. There have been efforts to reflect on the measures taken thus far calling to include a wider perspective of health that considers social, mental and non-COVID-19 health conditions, particularly for older persons, and to use the current pandemic as an opportunity to rethink the traditional public policy response regarding the needs of this population group [73]. Interestingly, a longitudinal study monitoring the quality of life in a national cohort in Chile before and during the COVID-19 outbreak found an increase in resilience during the pandemic: “Although some physical and mental health indicators have worsened during the pandemic, older adults mobilized resources that could allow them to maintain their quality of life, such as improved resilience” [74].

### 2.6.2. New Zealand

#### (a) Dementia prevalence and incidence

Little is known about the epidemiology of dementia in New Zealand since there has never been a national prevalence study [75]. There are currently an estimated 70,000 New Zealanders living with dementia [54]. By 2050, this number is expected to almost triple to 170,000 [54]. “The economic cost of dementia to New Zealand increased by 75% between 2011 and 2016, with the total cost of dementia to New Zealand in 2016 estimated to be

NZD 1.7 billion increasing to NZD 4.6 billion by 2050. People with dementia and their families/whānau face significant financial impact from the cost of health and social care and from reduction or loss of income” [54].

(b) Dementia strategy

In 2010, New Zealand launched its first dementia strategy [76]. Since then, a number of policy papers have been published including the “Improving Dementia Services in New Zealand-Dementia Action Plan 2020 to 2025” [54]. This Action Plan outlines four objectives for the coming years: (1) reducing the incidence of dementia; (2) supporting people living with dementia and their families/whānau care partners/supporters to live their best possible lives; (3) building accepting and understanding communities; and (4) strengthening leadership and capability across the sector [54].

(c) Current developments in research

In New Zealand, research in the context of aging including dementia has considerably increased over the past decade. Current health-related research is characterized by addressing the diversity of its population. For example, the Life and Living in Advanced Age: A Cohort Study in New Zealand (LILACS NZ) was started in 2010. This longitudinal cohort study aims to determine the predictors of successful advanced aging and understand the trajectories of health and well-being in advanced age in a Māori and non-Māori New Zealand population. It was found that ethnic disparities in medical conditions were present, with Maori being more likely—amongst other conditions—to have dementia. [77]. Similarly, differences have been found not only with regard to Māori presenting at a younger age to memory clinics [78] but also with regard to the use of antipsychotics that increased the risk of death threefold in Māori and Pacific Islanders, compared to New Zealand Europeans [75]. What it means to live with dementia from a Māori perspective has been explored only very recently [79].

(d) Reactions to the COVID-19 pandemic

Similar to developments in other countries around the world [80], in New Zealand, the use of information and communication technologies grew exponentially and gained importance in facilitating the delivery of psycho-social interventions. For example, in a 12-week pilot project, it was shown that cognitive stimulation therapy with some adjustment (e.g., smaller groups) was well accepted and easy to deliver using a videoconferencing platform (Zoom) for those people living with dementia who had access to an electronic device and a person facilitating the contact (e.g., a family member) [81].

### 2.6.3. Germany

(a) Dementia prevalence and incidence

There live an estimated 1.6 million people with dementia in Germany, with this number expected to increase to 2.4–2.8 million by 2050 [82].

(b) Dementia strategy

In 2012, the “Alliance for People with Dementia” laid the foundation for concerted actions in developing the National Dementia Strategy which was launched in 2020 [55].

(c) Current developments in research

With an estimated 51,000 people living with dementia with a migration background [82], there is an increasing interest in gaining insight into the culturally sensitive needs of this diverse population in Germany as well as in other European countries [83]. Under the umbrella of the “Alliance for People with Dementia”, a number of research efforts have focused on providing timely and adequate care and support, e.g., by overcoming the fragmented health care system [84]. More recently, the focus of research is shifting towards involving those affected by dementia in the research not only as the ones providing data but also as research partners [85].

(d) Reactions to the COVID-19 pandemic

Overall, the perceived access to health care services was positive in 2020 [86]. However, a study conducted on the utilization of health services by older persons found that dementia was diagnosed less frequently during the first lockdown (March–May 2020) in Germany [87]. As in many other countries, concerns and research output in this context have focused more on residential care settings and less on the community [88].

### 2.7. Research Objectives and Research Questions

By using the “learning across countries” approach involving Chile, New Zealand and Germany that represent different health care systems as well as different geo-political-cultural-social systems, we will derive universal principles that have relevance for others, i.e., participating countries as well as non-participating countries. We will identify aspects of resilience/resilient health care systems with regard to community-based care for people living with dementia and their families, thereby (a) fostering resilience in people living with dementia and their families; (b) fostering resilience in support structures; and (c) fostering resilience in health care systems. With this three-country exploratory comparison, we will contribute towards an internationally overlooked research setting (community care), we will contribute to a gap in research involving LACs by including Chile, where the implementation of sustainable community support structures in dementia has only recently commenced, and we will contribute towards increasing the understanding of dementia and responding to the needs of people affected by dementia from diverse socio-economic, socio-cultural and ethnic backgrounds.

With this research, we aim to answer the following research questions:

1. How have three selected nations (Chile, New Zealand, Germany) responded to the needs of people living with dementia and of their families prior to and during the COVID-19 pandemic?
2. How does living in countries with continuous natural hazards and risks impact on building resilience and enabling responses to rapid (respiratory) pandemics such as the COVID-19 pandemic, on the one hand, and to long-term challenges such as dementia, on the other hand? How might this differ in countries with (currently) fewer natural hazards and risks?
3. What can we learn from those global experiences to empower health care systems to provide adequate, equitable and sustainable care and support for families living with dementia during times of pandemics and beyond?

### 3. Methodical and Methodological Considerations

The following outlines useful steps towards a methodology with regard to the proposed research involving Chile, New Zealand and Germany. These considerations will be further analyzed, evaluated and defined in upcoming workshops and discussions of the consortium of authors and collaborating partners. One of the first steps will be to establish a tailored methodology considering the capabilities of each country and the diagnosis of the situation.

*Multi-disciplinary approach:* With this proposed research, we will move at the crossroad of global health (“global health” can be defined as “collaborative trans-national research and action for promoting health for all”, where global health is concerned with all strategies for health improvement, at a population level, as much as focusing on individuals, “and across all sectors, not just the health sector” [89]), health care system approaches and disaster management. Linking those three major perspectives under the denominator dementia will require a change in perspective from each partner. We will investigate which measures were taken globally and what works for whom and why in terms of demand, access and utilization of dementia community care by assessing qualitative and quantitative data and potentially drawing upon health economic analyses. We will describe each country’s health system. Additionally, we will evaluate aspects of attitudes such as disaster readiness and disaster history (e.g., how do countries draw on expertise

gained from other disasters) or trust in governments. Socio-economic, socio-cultural, political and geographic factors will be considered for both the public services and the population.

*Strengths-based approach:* Furthermore, we will embrace a dynamic concept of health as “the ability to adapt and to self-manage in the face of social, physical and emotional challenges” [17]. This definition reflects the human capacity for resilience and for coping with new situations, addressing the long-standing criticism of the somewhat static WHO definition as “a state of complete physical, mental and social well-being” [90]. The WHO definition of health does not adequately reflect the human capacity to live well despite a disease. The revised concept, however, is a phenomenon that can be described increasingly often with the rise in chronic illnesses and an increasingly aging population around the globe [17]. Applying the framework of health defined by Huber et al. [17] as the ability to adapt and self-manage to dementia allows a focus on capacities and on deficits by connecting physical, mental and social health [18].

*Resilient health-systems approach:* Trying to understand the impact of the COVID-19 pandemic and the underlying mechanisms in order to identify aspects of resilience and potential for system strengthening suggests a systems approach [91] as well as the need for collaboration across all sectors [28]. The WHO has defined six “building blocks” that make up a health care system: (1) health services; (2) health workforce; (3) health information system; (4) medical products, vaccines and technologies; (5) health financing; and (6) leadership and governance (stewardship) [92]. While those “building blocks” undeniably make up the core elements of our health systems, for this proposed research, we will adopt a more analytical understanding by considering the interrelations of those core elements following the critique of this definition offered by Julio Frenk [93]. We will include those affected not just as a beneficiary of a health system but as an essential part of it, and we will include aspects of equity and intrinsically valued goals of health systems beyond “improving health” [93]. With this, we will be able to take into account the characteristics of complex adaptive systems such as the non-linearity of effects or interactions between the health system building blocks [94]. Such reasoning is well reflected in the health systems resilience framework that Haldane et al. developed to analyze system resilience during the COVID-19 pandemic in 28 countries: based on the WHO’s health systems building blocks framework elements of resilience which are centered around community engagement as the core to all elements of health systems resilience. Underpinning these elements are health equity and health outcomes [28]. With the analytical lens of resilience characteristics (awareness, diversity, self-regulation, integration, adaptability, continuity, sustaining gains and fostering people-centeredness), this might serve as a framework that we can apply to the specific focus of dementia care before, during and after the COVID-19 pandemic. Furthermore, we will also consider the health systems framework developed by Murray and Frenk [95] that might offer a more comprehensive approach by focusing on general health system elements and approaches existing independent of a pandemic scenario.

*Participatory approach:* There is growing attention toward engaging patients, community members and other stakeholders in research to enhance the relevance of findings and accelerate the implementation of change. Persons living with dementia are usually considered vulnerable, and indeed, they have been disproportionately affected by this pandemic. However, we want to challenge this perspective that feeds into stigmatization [96] and rather include the voice of people living with dementia by taking a participatory research approach [85,97]. We will collaborate with experts, stakeholders and “experts by experience” internationally to identify best practices and derive strategies for adequate and equitable home care provision for people with dementia applicable beyond the COVID-19 pandemic. Participatory research in the context of dementia has gained increasing attention over the past decade [85,98]. Similarly, in disaster research, there is a strong call for the inclusion of those most vulnerable in disaster situations (including older

persons) at all stages of planning to address the specific needs of this group adequately and avoid adverse outcomes [99].

*Implementation and system learning:* By describing elements in each system that seem to be “stories of success” and by describing the facilitators and barriers to those, we will likely be able to provide guidance on the implementation of best practice examples for other health care systems. This research will be guided by the multi-level conceptual framework proposed by Chaudoir et al. [100] to measure factors affecting the implementation of health innovations. The scalability of innovations across a region or country can be assessed using the Intervention Scalability Assessment Tool [101]. Furthermore, we will adopt a dynamic understanding of sustainability whereby the evolution of interventions is a prerequisite for constant quality improvement and a learning health care system [33]. Therefore, we will apply the Dynamic Sustainability Framework that supports continued learning to advance the implementation, transportability and impact of health services research [33].

*Translational approach:* The context of dementia can be understood as a magnifying glass for health care and system challenges beyond the dementia context. By examining a phenomenon specifically focusing on the context of dementia, it can be expected that the results of this study will be applicable to other health contexts as well as other pandemics. We believe that there is translational potential with regard to, first, the ability to cope with geographical risk and the applicability of such knowledge/experience/attitude to a pandemic; second, the ability to respond to a pandemic as a challenge for the entire health care system, and the applicability of findings to the specific context of dementia care; and third, the applicability of findings in relation to a crisis to other pandemics and times without crises.

We will consider a time-related analytical component, gaining insights into the level of (iterative) *acute, post-acute and long-term crisis* adaption at an individual, organizational and national level. This will allow us to analyze time-sensitive decisions taken by governments and translated into practice by stakeholders.

#### **4. Arguments in Support of Our Vision and Agenda**

This section will provide the first insights in support of our vision for research and learning across three countries, Chile (Latin America), New Zealand (South Pacific) and Germany (Europe).

##### *4.1. The Need for a Complex Approach*

The mitigation and containment of the ongoing COVID-19 pandemic relies heavily on behavioral changes [102]. However, various aspects influence the extent and speed of behavioral changes including social norms, social inequalities, culture and political polarization [103]. Additionally, a population’s acceptance, compliance or adherence regarding behavioral changes is of utmost importance, but it does require a relevant degree of trust, motivation and readiness. While trust in the government might be high in Germany [104] and New Zealand, in Chile, trust in governmental actions and policies is low. For example, in October 2020, New Zealanders re-elected Jacinda Ardern and the Labour Party with 50% of the votes [105]. Around the same time, 78% of Chileans voted for a constitutional referendum [106]. Whereas New Zealand went into a full lockdown early on, resulting in very low incidence and mortality rates [107], in Chile, political protests—sparked over the rise in price of metro tickets months before the outbreak of the COVID-19 pandemic—continued during the lockdown in April [108]. This suggests that also past experiences such as a country’s history in terms of diseases, culture and political systems work as mediators that influence the acceptance of containment measures [109,110].

In order to influence public behavior, the dissemination of trustworthy information plays a vital role [103]. While it is understandable that governments rely primarily on experts of scientific knowledge, especially virologists, to drive their decision making during a pandemic, such a narrow base of knowledge becomes problematic when the social

dynamics of populations are involved. For example, what can be observed in the context of the COVID-19 pandemic is the phenomenon of spreading misleading and false information labeled as an “infodemic” [111]. Analyses from LACs including Chile echo pre-pandemic findings showing that periods of uncertainty and fear lead to the dissemination of false information [112]. Additionally, New Zealand researchers have shown that preparedness in the context of aging is an adaptive concept that extends beyond disasters and is linked to personal preparedness and social relationships [113]. They concluded that understanding the role of preparedness in the everyday lives of older adults has implications for improving the disproportionate negative outcomes this vulnerable age group can experience during a disaster, and that health, gerontology and emergency management should work collaboratively and “consider the bigger story of aging in the community” [113]. Building on this notion, we strongly believe that, in addition to a multi-directional learning approach with involved countries learning *from* each other, a multi-disciplinary team from diverse academic as well as non-academic backgrounds is needed to address disaster research in dementia. Considering all aspects taken together, it is clear that the complexity of human action and interaction within complex systems (including the health system, the science system and the political system [114]) cannot be ignored when approaching the question of how resilience is being built to strengthen health care systems in the of context of dementia and in future pandemics.

#### *4.2. Insights and Lessons to Be Learnt from a Trilateral Country Comparison between Chile, New Zealand and Germany*

Conducting a comparison between Chile, New Zealand and Germany is likely to provide learning effects at different levels. Some preliminary potential insights have already been gained through consulting dementia experts within the research team and stakeholders representing national policy perspectives. Three examples shall be presented here.

First, all three countries have a strong interest in overcoming their fragmented health care systems. While New Zealand is currently centralizing its regional structure of 20 district health boards, and Germany has initiated local dementia care networks to overcome fragmentation, Chile is on the verge of inaugurating a new constitution that will lead to a more accessible and equitable health care system. However, inequity is likely to be defined differently in the three countries; for example, Chile might be more aligned with New Zealand in improving access to care for their indigenous populations.

Second, while highly standardized procedures such as evacuation plans usually come into place as an initial response to biological, geophysical or hydro-meteorological hazards (or disasters) [115], for people living with dementia, the transition from their usual place of care is associated with increased morbidity and mortality [116,117]. Beyond this initial recovery stage, people living with dementia might need a different type of support, a support that is adaptable, flexible and accepting of people that seem to diverge from what is considered “normality” by a majority. It is likely that differences in culture and hazard exposure levels will provide hints on factors shaping the attitudes towards disasters as well as dementia.

Third, a comparative study will allow us to reflect on the increasing struggle for sustainability of health care systems and the loss of relationship-based care for people living with dementia in its course. It might be that an open-minded, multi-cultural [118] and welcoming society [119], such as New Zealand, has a stronger emphasis on the community that might carry through to the patient level and those involved in the care of a person living with dementia. Similarly, countries such as Chile and New Zealand, whose age structure is approaching an upside-down pyramid-like structure, could learn from Germany, where the financial base for an older majority is relying on a younger minority.

The challenges of using a comparative approach and the potential for learning are well recognized [34], and examples can be found in previous trilateral health care studies: comparing access to HIV diagnosis for indigenous populations in Canada, Australia and

New Zealand [120]; palliative care strategies in advanced dementia in Israel, the US and the Netherlands [121]; and the cost-effectiveness of dementia support structures in three European countries [122]. However, multi-lateral studies in the context of health care systems and dementia often remain at a largely descriptive level, with less focus on understanding the reasons for system development and the potential for learning from each other [34].

## 5. Conclusions

There is agreement amongst policy makers, health professionals and other stakeholders alike that the COVID-19 pandemic requires a global response, and the same is also true for research into this pandemic. However, establishing how to govern health system transformation in such a way that our health systems become more resilient to future pandemics and times without crises is a considerable challenge. The purpose of this proposed agenda is to address the disaster preparedness and disaster resilience of health care systems. We see translational potential that lies in cross-country learning (involving Chile, New Zealand and Germany) which will contribute towards adequate, equitable and sustainable care and support for families living with dementia during a pandemic and beyond. It is our vision that this research has the potential to contribute towards strengthening and transforming health care systems in times of crises and beyond.

**Author Contributions:** Conceptualization, F.L.U.; writing—original draft preparation, F.L.U.; writing—review and editing, F.L.U., O.A., W.B., G.C., S.C., A.F.-G., C.M.C., N.K., R.K., M.M.-L., R.A.S.R., L.S., A.S. and M.R. All authors have read and agreed to the published version of the manuscript.

**Funding:** This research was partially funded by grants supporting the research of Andrea Slachetky from ANID/FONDAP/15150012 and the MULTI-PARTNER CONSORTIUM TO EXPAND DEMENTIA RESEARCH IN LATIN AMERICA (ReDLat), supported by the National Institutes of Aging of the National Institutes of Health under award number R01AG057234, an Alzheimer's Association grant under the grant number SG-20-725707-ReDLat, the Rainwater Foundation, and the Global Brain Health Institute. The content is solely the responsibility of the authors and does not represent the official views of the National Institutes of Health, Alzheimer's Association, Rainwater Charitable Foundation, or Global Brain Health Institute.

**Acknowledgments:** The authors would like to thank the reviewers remaining anonymous for their valuable feedback. F.L.U. would also like to thank Franka Meiland and Jonathan Serbser-Koal from the DZNE site Witten for their feedback on an earlier version of this article.

**Institutional Review Board Statement:** Not applicable (not involving humans or animals).

**Informed Consent Statement:** Not applicable (not involving humans or animals).

**Data Availability Statement:** This article did not rely on datasets other than the cited literature.

**Conflicts of Interest:** The authors declare no conflict of interest.

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