

Integration of Older Adult Service  
Systems for Families with Dementia in  
Central America:  
A social network approach

Nereide Alhena Curreri

Word count 72,639

University of Stirling

Thesis submitted for the degree of Doctor of Philosophy

April 2020



## Declaration

I declare that I have composed this thesis myself and that the results are of my own research. I also declare that none of the work contained within this thesis has been submitted for any other degree at any other university.

Nereide Alhena Curreri

## Copyright

The copyright of this thesis belongs to the author under the terms of the United Kingdom Copyright Acts as qualified by the University of Stirling Regulations for Higher Degrees by Research. Due acknowledgement must always be made of the use of any material contained in, or derived from, this thesis.

*I dedicate this thesis to my Mother, Father and Brother.  
Because you believe in me.*

*This thesis was written in commemoration of Dr. Angel Pineda,  
1958 - 2018.*

*In loving memory of my nonna.*

# Acknowledgements

I must first express my gratitude to two special friends: Mauro and Daniela, you listened and encouraged me every step of the way. I couldn't have made it through without you.

A special thank you to my supportive supervisors, Dr. Louise McCabe and Dr. Dave Griffiths, who challenged me and guided me.

The completion of this project was made possible by the immense, warm welcome, cooperation, and friendship of the incredible people I had the honour to connect with in Guatemala, El Salvador, Honduras, Costa Rica and Panama.

Thank you Evelyn for your friendship and support. Thank you Jake for your friendship and gracious hospitality. Thank you Marco for your warmth and local knowledge.

Thank you Claudia for connecting me with Sonia. Thank you Sonia for your friendship, kind hospitality, and the amazing tours. Thank you Señora Zulema for your kindness.

Thank you Alba and Joel for your friendship and the delightful tours.

Thank you Brenda for your friendship and hospitality.

Thank you Adriano for your friendship, and a place to drink un caffè in company.

My deepest gratitude to the Alzheimer's association of Guatemala, Cecilia and both doctors Luna, for a tremendous openness to my research and me. You opened the door to Guatemala and Central America, providing an invaluable reference to your colleagues of the other Alzheimer's associations.

A special thank you to all of the Alzheimer's associations for your warm welcome and your kindness.

An endless thank you to all of the interviewees of the many organizations across the countries. To maintain confidentiality and anonymity, I express my appreciation to you as a group. Thank you for taking the time, and allowing me to know your stories.

Finally, a distinctive tribute to the families who generously allowed me into their lives and shared their stories with me. Your strength, courage, and love I will always remember.

I will forever be grateful to you all.

*Gracias.*



# Abstract

It is estimated that the global incidence of dementia will double by 2050 and that the majority of people with dementia will be living in developing countries. Developing countries are under-researched; data from Central America is scarce. A lack of coordination between service providers and across settings results in fragmented health care systems [6]. Therefore, organisation of older adult service systems, dementia specific services, and exchange between organizations, is needed [7]. Research on the key indicators of integrated care at the macro, or system level is scarce [8].

From a global health perspective, this study explores the interorganisational ties of service providers for older adults, and families with dementia. The target population of this study was providers of services for older adults and families with dementia in Guatemala, El Salvador, Honduras, Costa Rica and Panama. Sixty-eight (68) semi-structured interviews of representatives of: government, public, private, non-profit organizations, hospitals, care homes, universities, and families with dementia, were completed. The types of ties, strength of ties, and types of exchange were assessed together with the analysis of 4 network properties: density, centrality, E-I index, and QAP correlation.

This study provides primary data on: integration levels of older adult service systems based on Leutz's levels of integration (1999); insight into services provided; and structures of five developing countries' older adult service systems. 304 ties, between 167 organizations were explored. Findings portray a quid pro quo culture of exchange between organizations with underlying strong, collaborative ties. Families are excluded in the exchanges, and consistently unaware of services especially those specifically for dementia.

In general, system density and centrality measures were low, correlation among networks was not significant, indicating fragmentation and low integration. Yet the systems also included multiple high indicators of linkage development, such as exchange of resources and information, external ties, and an overall sense of collaboration.

In conclusion, SNA provides an effective methodology for evaluating integration levels of care service systems in developing countries through understanding who the actors are and the relationships between them. The findings of this study influence policies on partnership working and suggest new inter-organizational practices leading to increased system integration and consequently increased provision/receipt of services for families with dementia.





# Table of Contents

Abstract.....	7
Table of Contents.....	9
List of Figures.....	12
List of Tables.....	13
Chapter 1: Introduction to Thesis .....	15
Introduction.....	15
Dementia .....	17
Integration.....	18
Research questions.....	20
My background .....	21
Thesis structure .....	23
Chapter 2: Literature Review.....	27
Introduction.....	27
Dementia .....	28
Approaches to Dementia and Care .....	29
International Ageing and Dementia Policy.....	46
National Dementia Plans .....	52
Integrated Care and Integration.....	56
Models of Implementation.....	58
Integration in Dementia Care.....	61
Models for Assessing Integration.....	62
Integration in Developing Countries.....	65
Conclusion.....	66
Chapter 3: Methodology.....	67
Introduction.....	67
Critical Realism.....	68
International Comparative Research .....	70
Social Network Analysis .....	76
Integration.....	83
Reflection.....	84
Research Design .....	84
Ethical Approval.....	88
Consent from Participants .....	88
Data Collection .....	92

Construction of Data .....	101
Data Analysis.....	103
Data management .....	106
Conclusion.....	106
Chapter 4: Central America .....	108
Introduction.....	108
The Birth of Nations.....	108
Similarities and Differences .....	111
National Health Systems .....	114
Legislation for Older Adults.....	116
Inter and Intra Regional Integration .....	117
Conclusion.....	120
Chapter 5: Regional and National Services .....	121
Introduction.....	121
Services in the Region.....	121
National Perspectives .....	151
Conclusion.....	157
Chapter 6: Connecting .....	158
Introduction.....	158
The Nodes .....	159
Type of Tie.....	164
Reciprocal ties .....	167
Strength of Tie .....	171
Exchange.....	176
Dementia specific findings .....	188
Conclusion.....	193
Chapter 7: Collaborating .....	196
Introduction.....	196
Whole Networks .....	198
Density.....	204
Closeness Centrality.....	208
E - I Index .....	218
QAP Correlation .....	220
Dementia Specific Networks.....	226
Family networks.....	233
Conclusion.....	239
Chapter 8: Discussion .....	241

Introduction.....	241
Research Findings.....	242
Impact and Implications.....	254
Limitations .....	259
Further Research.....	259
Conclusion.....	260
References.....	262
Appendices .....	285

# List of Figures

Figure 1 Nested Systems .....	23
Figure 2 Biopsychosocial Model of Health .....	36
Figure 3 Ecological Systems Theory of Health (Bronfenbrenner 1977) .....	37
Figure 4 Global dementia policy making organizations .....	47
Figure 5 Latin American countries with a national dementia plan (ADI 2020) .....	55
Figure 6 Structure of integrated primary care (Valentijn et al. 2015) .....	60
Figure 7 Quality of Care Model .....	63
Figure 8 Dimensions of human service network integration .....	63
Figure 9 Part II of interview guide.....	86
Figure 10 Inter-regional integration .....	118
Figure 11 Phase 2 exchange coding.....	177
Figure 12 Phase 3 exchange coding.....	177
Figure 13 Resources theme of exchange .....	180
Figure 14 Legend of colour for type of node .....	199
Figure 15 Guatemala: whole network.....	199
Figure 16 El Salvador: whole network.....	200
Figure 17 Honduras: whole network.....	201
Figure 18 Costa Rica: whole network.....	202
Figure 19 Panama: whole network.....	203
Figure 20 Costa Rica exchange networks:.....	213
Figure 21 Guatemala: A. Strength of tie, B. Resources exchange .....	214
Figure 22 Guatemala: Resources and collaboration exchange.....	214
Figure 23 El Salvador: A. Collaborative ties, B. Collaboration exchange .....	215
Figure 24 Honduras: A. Referrals exchange, B. Resources and collaboration exchange .....	216
Figure 25 Panama: A. Collaborative type of tie, B. Resources exchange .....	216
Figure 26 Guatemala: Dementia specific ties.....	228
Figure 27 Guatemala: Referral exchange .....	229
Figure 28 El Salvador: A. Dementia specific ties, B. Referral exchange .....	229
Figure 29 Honduras: A. Dementia specific ties, B. Referral exchange .....	230
Figure 30 Costa Rica: A. Dementia specific ties, B. Referral exchange.....	231
Figure 31 Panama: A. Dementia specific ties, B. Referral exchange .....	232
Figure 32 Guatemala: networks with families.....	234
Figure 33 El Salvador: Networks with families .....	235
Figure 34 Honduras: Networks with families .....	236
Figure 35 Costa Rica: Networks with families .....	237
Figure 36 Panama: Networks with families .....	238

# List of Tables

Table 1 Older adult and dementia global policies.....	49
Table 2 Number of organizations by country.....	85
Table 3 Snippet from fieldwork data 2018 workbook.....	102
Table 4 Intra-regional similarities and differences.....	112
Table 5 Population in Central America.....	113
Table 6 National Laws for Protection of Older Adults.....	116
Table 7 Organizations present in country networks.....	123
Table 8 Commissions on ageing by country.....	124
Table 9 Alzheimer's associations by country.....	126
Table 10 Families with dementia by country.....	129
Table 11 Care homes by country and type.....	132
Table 12 Number of organizations in networks.....	160
Table 13 Types of nodes.....	161
Table 14 Number of organizations by type and country.....	163
Table 15 Type of tie coding phases.....	165
Table 16 Type of tie by country.....	165
Table 17 Type of node in type of tie by country.....	166
Table 18 Reciprocity matrix Honduras.....	168
Table 19 Reciprocal ties of interviewed organizations by country.....	169
Table 20 Type of node in reciprocal tie.....	170
Table 21 Strength of tie by dimension, country and score.....	172
Table 22 Total strength of tie scores by type of node.....	173
Table 23 Information exchange scores.....	178
Table 24 Referral exchange scores.....	179
Table 25 Resources exchange.....	180
Table 26 Number of responses in collaboration subcategories.....	181
Table 27 Collaboration exchange scores.....	182
Table 28 Nothing exchange scores.....	182
Table 29 Ties exchanging nothing by type of node.....	182
Table 30 Multiplex ties.....	184
Table 31 Multiplex ties by type.....	184
Table 32 Multiplex exchange by type of node.....	186
Table 33 Collaborative type in multiplex tie.....	187
Table 34 Number of dementia specific organizations in networks.....	188
Table 35 Interviewed dementia specific orgs by type of node.....	189
Table 36 Dementia specific types of ties.....	190
Table 37 Reciprocal ties of interviewed dementia specific organizations.....	191
Table 38 Strength scores for dementia specific ties by dimension.....	191
Table 39 Exchange scores of dementia specific ties.....	192
Table 40 Multiplex exchange in dementia specific ties.....	192
Table 41 Network density by integration indicator and country.....	207
Table 42 Network density by exchange network.....	207
Table 43 N Network closeness centrality by integration indicator.....	211
Table 44 Network closeness centrality by exchange network.....	211
Table 45 Closeness centrality and type of node by integration indicator.....	212
Table 46 Closeness centrality and type of node by exchange network.....	212
Table 48 QAP correlation scores by network: Guatemala.....	221

Table 49 QAP correlation scores by network: El Salvador .....	223
Table 50 QAP correlation scores by network: Honduras.....	223
Table 51 QAP correlation scores by network: Costa Rica.....	224
Table 52 QAP correlation scores by network: Panama .....	225
Table 53 Dementia specific network property measures .....	227

# Chapter 1: Introduction to Thesis

## Introduction

In a global ageing context, prominent institutions such as the World Health Organization (WHO) and Alzheimer's Disease International (ADI) (WHO and ADI 2012) as well as researchers (Prince et al. 2013, Gonzalez et al. 2014, Stokes 2015, Barrett 1996) estimate, as of 2015, low to middle income countries (LMIC) to be the future home to the majority of the world's older adults and more specifically to the majority of people with dementia. Ageing populations are projected to continue to grow more rapidly in low to middle income regions like Latin America (Age International 2015, Prince et al. 2015). Of the world's population of over 60, it is estimated that in 2050 the majority will be living in the LMIC (Prince et al. 2013, WHO 2017, Gonzalez et al. 2014). In a literature review of 273 studies on the global impact of dementia, Prince et al. (2015) found that it is estimated that 40 million people live with dementia in LMIC and that by 2050 it will double to 80 million.

It is expected that Central America will experience an increase in prevalence of dementia higher than any other region by 2050, primarily due to population ageing (Stokes 2015, Manes 2016). Yet Central America is under researched (Prince et al. 2013, Cullell 2012, Kalaria et al. 2008). Latin American countries persistently lack research in dementia (Prince et al. 2015). Furthermore, the smaller Central American states are omitted in Latin American comparative studies, favouring the bigger countries such as Brazil, Mexico, Chile and Argentina (Cullell 2012). The literature points to a dearth of research into dementia in LMIC including data on formal and informal care arrangements (Prince et al. 1997, 2000, 2004, 2008, 2013, Russ et al. 2012, Kalaria et al. 2008; WHO 2000) to provide more robust data as dementia specific services may not exist in all LMIC (Volpe et al., 2020). "Further studies including countries from all World Bank [income] categories are highly needed to provide a more reliable picture of dementia care at the world level" (Volpe et al., 2019).

Dementia affects cognitive functioning, which in turn may also impact an individual's physical and social realms (WHO 2017, Barnes 2002). People with dementia thus may have complex needs extending beyond one health discipline. Cognitive decline may affect an individual's ability to live independently, to accomplish activities of daily living such as bathing, dressing, grooming, meal preparation and eating, walking, transferring, and toileting (Mlinac and Feng 2016, Giebel et al. 2019). The ability to perform other activities instrumental to daily living such as grocery shopping, cooking, and managing medicines and finances, may also be impaired by cognitive decline (ibid). This potential and variable decline in functional abilities creates biological, psychological, and social needs that can be best addressed through the integration of health and social care sectors (de Carvalho 2017, Nicaise et al. 2013, Fox et al. 2013, Provan and Milward 1995, Bunn et al. 2017).

The integration of health and social care leads to increased access to diverse services and continuity of care for families with dementia (Davis 2012, Hsiao et al. 2019, Minkman et al. 2009). Reducing the treatment of dementia as an isolated condition can be accomplished through the integration of services (Bunn et al. 2017). Yet, de Carvalho et al. (2017) indicate that in low-income countries, models of care system integration are rare, as is their evaluation. The WHO (2010) and Blanchet (2012) recommend that understanding how the systems of developing countries are structured will help to design improvement interventions.

In this thesis, I explore the older adult and dementia service systems of five Central American countries: Guatemala, El Salvador, Honduras, Costa Rica and Panama. Taking a social network approach to assess the inter-organizational ties between service providers, I am able to demonstrate networks of various types of interactions. I will demonstrate that these countries have service systems based on strong and collaborative ties and on exchange, which lay the foundations for system integration.

In this chapter, I will first introduce the underlying concepts of this thesis, dementia and health system integration, and indicate the gaps in the literature. Next, I will outline the research questions guiding this study, and provide a brief professional



biography to give context to my interest in this research. Lastly, I will present the subsequent chapters of the thesis.

## Dementia

Dementia is a syndrome presenting a variety of symptoms, caused by different diseases and conditions; it is not a disease (Jack et al. 2019, Swaffer and Low 2016, Whitehouse and George 2008, Bond 1992). The World Health Organization (WHO) defines dementia as:

“a syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (...) beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected. The impairment in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation” (WHO.int 2020).

This definition exposes the core of the biopsychosocial model of health (Engel 1977), which is based on the theory that an individual’s health is a sum of the interactions of its biological, psychological and social dimensions. The key point of the biopsychosocial model of dementia is the necessity to acknowledge and evaluate an individual’s health through the interactions between their various dimensions. If an individual’s health is to be viewed through interconnected dimensions, or disciplines, the service system must be interconnected. In order to accomplish this, health and social care services must be integrated, or interact in collaboration. Interactions therefore, become the basis for dementia care at the micro level, and at the macro level.

The biopsychosocial model and other approaches to framing dementia and modelling care practices will be discussed in depth in the next chapter. In this study, the biopsychosocial model of health is used to frame the variety of needs an individual with dementia may have, underlining a required multidisciplinary approach to care. Evidence indicates that people living with dementia have a high

incidence of comorbidities, not only caused by dementia symptoms (Bunn et al. 2014, Formiga et al. 2009). Multiple morbidities lead to complex needs, and to improve care, service models must incorporate this complexity (Schubert et al. 2006). Persons with multi-morbidities, at least 2 concurrent chronic conditions, such as people living with dementia, require multidisciplinary, coordinated care (Leijten et al. 2018).

## Integration

For people with multiple needs such as those with dementia, it is particularly difficult to navigate a commonly fragmented care and support system (Downs and Bowers 2014). The organisation of dementia specific systems of services and exchange between associations is needed (Fox et al. 2013) because clients with conditions that have multiple needs have more difficulty being responsible for effectively coordinating their own care and treatment through a myriad of service agencies [in the European and North American contexts] (Provan and Milward 1995). “A vivid and strong network of care providers is essential for delivering quality case management” (Minkman et al. 2009, p6). Although, according to Bunn et al. (2014), there is a lack of evidence of system structures and coordination of services for individuals with complex needs such as those with dementia and comorbidities.

A strategy of coordinating complex services for diverse populations is the formation of networks of integrated services (Browne et al. 2007). The literature points to the obstacles of accessing services, and obtaining continuous care, as deriving from the division between health and social sectors and inadequate collaboration between disciplines (Jelley et al. 2019, Volpe et al. 2020, Bunn et al. 2017, Hsiao et al. 2019, Heckman 2019). The shift in focus, advocates the WHO (2017), must be from disease and health systems to care and support services designed for people. The Integrated and People-Centred Health Services Framework, (WHO) launched in 2016, emblemizes it. The vision is based on universal health through coordinated and comprehensive services, provided by

collaboration and integration across sectors, disciplines, organizations, settings, providers and users (ibid). Different kinds of integration exist, directed at whole populations or specific groups with the same conditions, and involving the coordination of services (Ham and Curry 2011, Kodner and Spreeuvenberg 2002, Valentijn et al. 2015, Strandberg-Larsen 2011, Kumpers 2005, Macadam 2008). Some of the different concept definitions of integration and integrated care are provided in the next chapter. Suffice to summarise here that for this study, population based integration, at the macro, system level, across older adult and dementia service organizations, is the focus.

Integration is paralleled to (w)holism from its etymology, and thus intended as not only the sum of parts, but also the sum of the interactions of those parts to achieve their individual goals and consequently the greater goal of the sum (Kodner and Spreeuvenberg 2002). Adapted into care service systems, integration implies a setting where providers are inter-connected, striving to meet individual objectives, as well as an ultimate collective aim of quality care provision (Nies and Berman 2004). But Milward and Provan (1998) advise, before investing time and money into integrating services, an attempt should be made to establish how integrated a system is.

According to Bloom and Standing (2008), a health system focuses on relationships and how they can provide services. Relations between organizations have been studied by organization theorists since about the early 1960s (Provan and Milward 2001), and social network analysis (SNA) is a methodology that has been used to explore and analyse relationships since the mid-20th century (Scott and Carrington 2011, Borgatti et al. 2009, Knoke and Yang 2011, Leavitt 1951). The boundaries and performance of a health system in developing countries can be more easily studied through SNA (Blanchet and James 2012). Network pattern similarities or differences may be viewed regardless of national circumstances, policies and imagined or intended organizational structure (Nicaise et al. 2013). Nevertheless, according to Blanchet and James (2012), SNA has seldom been employed to assess health systems of developing countries.

Social network analysis as a methodology was used in this study to investigate the inter-organizational interactions and patterns of interactions amongst older adult and dementia services providers in five Central American countries. Through an evaluation of the inter-organizational ties and the networks they create, the levels of integration of the older adult and dementia service systems were assessed. The attributes emerging from the data such as: type of tie, strength of tie, reciprocal ties, types of exchange, and dementia specific ties, were explored. These attributes were consolidated with measures of four network properties: density, centrality, E-I index and QAP correlation, as will be explained in detail in the findings chapters.

The attributes and the network properties act as indicators of integration (Blanchet and James 2011, Morrissey 1985, 1994, Rosenheck et al. 2000, Milward and Provan 1995, 1998, Micaise et al. 2013, Wang et al. 2016, Davis et al. 2012, Raeymackers 2013). Additional concepts were applied such as the “Goldilocks Principle” (Valente et al. 2015, p.7) to understand how the results of the analyses of the indicators demonstrate integration.

This thesis intends to extend the body of literature on health and social care integration in LMIC, focusing specifically on the older adult and dementia services systems in Central America.

## Research questions

In order to add to the existing body of knowledge described above, the objectives of this study were to investigate the integration levels of the older adult and dementia service systems of Guatemala, El Salvador, Honduras, Costa Rica and Panama. Through an exploration of the interactions between service providers and the networks created, by means of social network analysis, integration will be assessed.

To support this aim the research explored the following questions:

- How are older adult services structured in Central American countries? What are the relevant regional and national policies, what services are offered; what types of services are dementia specific?
- How integrated are the networks? What integration levels do the node and tie attributes suggest; what integration levels do the network measures suggest?
- How do the dementia specific networks compare to the whole networks? How do the positions of families in the networks offer insight into their receipt of care/support services?

## My background

My experience in, and passion for working with people living with dementia led me to this PhD journey. At 25 years old, I accompanied my maternal grandfather in his last weeks, days, and breath. I did not realize the profound impact that had, together with my deep attachment to and rooted sense of loss of my paternal grandmother, until I began studying gerontology. After an initial one-year certification, I decided to proceed with a European Master's degree in the same field. The theories of quality of life, prevention, and psychological, social and physical interdependence enraptured me. I was enthusiastic and felt prepared to help people and to catalyse change in practice. What I had yet to learn was the lived experience of mortality, pain, disease, care practices, health systems, and navigating through them all. From Italy to the United States, I worked in nursing homes and in home care. As a geriatric care manager with a caseload ranging from 40 to 70 families, I assisted people in all levels of care: independent, assisted living, dementia, skilled nursing, hospice care, and bedridden; from all socio-economic backgrounds. I became specialized in assisting people and families living with dementia, and came to recognize the burden of navigating care systems.

The opportunity to start-up a dementia unit was serendipitous. A residential care facility, part of a national chain, was in the process of remodelling and implementing a dementia care safe unit within the new model. I was hired to start from scratch, with the collaboration of a nurse practitioner as supervisor, to develop the care structure of the 16-suite unit. Through avid research, criteria given by state and local regulations, and guidelines from the headquarters' management, I set up the unit, which included a dementia garden, the care processes for staff, the care plans, and the daily activities routines. Evaluating would be residents for admission was one of the most eye opening responsibilities. Teamed with a nurse, we visited families' in their homes to assess the physical and psychosocial wellness of the person living with dementia. It was in this phase that my observational skills and senses were heightened to capture as much as possible in order to make a robust case for the person's appropriateness to the unit. While the nurses managed medications and physical symptoms, we worked in tight partnership in ensuring residents' holistic well-being via regular needs assessments. In addition, I directed the psychosocial aspects of the residents, their families and staff, through family and staff meetings and events, via consistent monitoring.

The study and application of gerontology changed my life completely. After having worked as an actor and model in the superficial and shallow world of television and fashion, I decided to return to university to find my life's higher purpose. My choice of study forced me to confront my own existence and the human experience as a whole. More specifically, I witnessed death repeatedly. Not only biological death, but also the multi-faceted losses perceived by the families of people living with dementia.

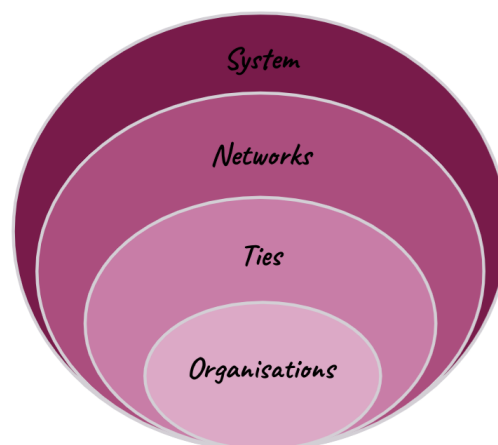
It became clear to me that the management, coping, operations, and governance involved in living with and caring for someone living with multi-morbidities or chronic illness are the key aspects to maintaining the highest possible quality of life for all (patients, carers, health and social care staff). Through my work experience, I tackled the disconnection amongst services, the complexity of the health systems, and the difficulty in receiving timely and appropriate assistance. Additionally, I came to the realization that healthcare systems for the ageing

demographics, and especially for families with dementia, needed to become more accessible. Partaking in implementing changes led me to seek information about dementia care services around the world, especially in developing countries where dementia is less acknowledged and health systems less developed. Visiting Central America was a long time wish, having connected, lived, worked with people and the cultures of the region while living in California, a mecca for emigrants from Central American countries. It thus became the perfect scenario for a return to academia. I searched for a supportive base in psychosocial dementia research, among the global myriad of bio-medical and neurological university departments, and found the Dementia Services Development Centre linked to the University of Stirling.

## Thesis structure

I have structured the thesis in consonance with the nested format of the older adult and dementia service systems, which also shaped the analysis process. The systems are made up of networks that are made up of ties between organizations (Figure 1). Therefore, I discuss the findings of this study beginning from the micro level, in this case the organisations, and build in a bottom-up fashion to reveal the ties, and the networks they form.

Figure 1 Nested Systems



In chapter 2 I present the literature on the main concepts framing this study. I begin by outlining the evolution of approaches to dementia that underpin models of care. I explain how Engel's (1977) biopsychosocial model can be considered to incorporate the other models, hence its use to structure the rationale of this study. The second section of the chapter presents the concepts of integrated care and health system integration, and how they are linked to direct provision of care. Finally, calls from the literature for research on health systems in developing countries are indicated.

In chapter 3, I present and discuss the methodologies I used to shape the research design of this study. I introduce critical realism as the epistemological lens through which the research questions were examined and the research conducted. Within this frame, objective reality such as biological health is considered as interacting with subjective psychological and social experiences; and socially constructed interactions among care system disciplines and sectors are perceived through a positivistic reality of networks. Subsequently, the methodologies guiding the research, and how they, international comparison research approach and social network analysis, were applied in the research design, are discussed. Finally, the design and research process, such as selection of fieldwork sites, research tools, sampling methods, data collection and analyses, are outlined.

In chapter 4 I provide a window onto Central America as a region, offering a backdrop of the setting the research took place in. It begins with a brief history of the region, and a snapshot of the similarities and differences between the countries. Next, I present summaries on the general national health systems of the five countries included in this study: Guatemala, El Salvador, Honduras, Costa Rica, and Panama. This leads to a section outlining the existing legislation on the protection of older adults' rights and on the care and support for families living with dementia. The final section in this chapter highlights the efforts of integration within the region, and inter-regional, indicating an existing movement for cooperation.



Chapters five to seven present the findings from the research, delving into the micro level of the services and organizations in chapter 5, the meso level of ties in chapter 6 to the macro networks in chapter 7.

With chapter 5 through regional and national perspectives, I explore the older adult care services that are available, and offer cross-country comparisons of the principal organizations. Contemporaneously, fieldnotes and my observations offer insight into the individual organizations and the context. In addition, in this chapter I point to the outliers, services that are unique, only present in one country, and how they relate to the national climates surrounding older adult services.

In chapter 6, I delve into the intricacies of the interactions between organizations. Here I illustrate the categories that emerged from thematic coding of the interview guide responses. The six categories become the indicators of integration: types of nodes that are in the networks, types of ties that exist between the organizations, reciprocal ties where both nodes nominate having a tie with each other, the strength of the ties between the nodes, what is exchanged among the nodes, and dementia specific ties. The results of the analyses of the ties within each category are explained, and linked to levels of integration.

Chapter 7 delineates the immersion into the networks, which emerge from the findings of the categories analysed in the previous chapter. The analyses performed on the networks are described. I discuss four network properties which measure characteristics specific to the interactions within a set of organizations. How these properties are additional indicators of integration is discussed, and the findings are interlinked with dementia care and the system levels of integration.

In the final chapter, chapter 8, I present the key findings. I return to my research questions to discuss each, and the insights gained from this exploratory comparative study. The concluding assessments of the low level of integration for each national older adult and dementia service system are also discussed, as are the impact and implications for practice and policy of the findings. Next, the limitations of this study and recommendations for further research are outlined. In the concluding paragraphs, I highlight the contributions, and reiterate the central premises of this thesis, that to provide the level of integrated care needed to

effectively support families with dementia a care system must be integrated, and that interactions are indicators of integration.

# Chapter 2: Literature Review

## Introduction

Understanding the multiple needs of people with dementia is enveloped in a model of care that sustains the connections and interactions between disciplines.

Service providers making up the health and social care system partake in often undefined connections and interactions without specific goals. Developing the foundation for my research, I began by exploring the approaches framing dementia, which conceptualize their multiple needs, and how a health and social care system can meet them. Because it was impossible to detach myself from the research, I use the first person throughout.

In this chapter, I first summarise the methods used to complete this literature review. Next, I present the central ideas on which this thesis is based. In the first section, I provide a brief summary of dementia and an overview of the evolution of approaches to dementia care. In the second section, I outline the development of international ageing and dementia policies. The third section is dedicated to reviewing the literature on the concepts of integrated care and integration of health care systems, which I link to dementia care. Finally, I highlight the call from the literature for more research in developing countries.

## Methods

To achieve a quality narrative review of the literature, several methods were employed (Randolph 2009). Broad search terms initiated the search for literature: dementia, dementia care, integration, and integrated care, via EBSCO host web databases: CINAHL complete; Health Source: Nursing/Academic Edition; MEDLINE; Political Science Complete; PsycARTICLES; SociINDEX with Full Text. A second method used was reviewing reference lists of relevant articles. These offered significant sources. Google Scholar was an additional database used to search for full texts of specific articles, and to search for narrow terms to expand

on previously searched topics. Finally, the websites and journals of prominent organizations within each field were consulted for publications and some webpages were cited, for example from: United Nations, World Health Organization, Alzheimer's disease International, Dementia Alliance International, International Foundation of Integrated Care, and the International Journal of Integrated Care.

To sustain relevance and credibility of the sources, titles, abstracts, and journal provenance were reviewed and exclusion criteria were employed: date or historical relevance, clinical trials, focus on specific factors/morbidities, language other than English/Spanish/Italian; conference abstract; poster abstract; focus on egonets; measuring outcomes, performance, evidence; focus on outcomes. Inclusion of sources was based on their thematic alignment to this study's framing concepts. A primary reading of the sources retrieved prompted further filtering for pertinent content based on the narrowing important aspects of each topic. A final search was completed using Google Scholar to ascertain the literature review was up to date and included the most recent literature.

## Dementia

Dementia does not have one fixed meaning (Nedlund and Nordh 2015). Dementia is an umbrella term for symptoms associated with brain aging (Whitehouse & George 2008). It is a syndrome that affects older people in particular, a severe cognitive impairment that interferes with an individual's activities of daily living and is progressive (Knapp 2007, Rossor and Knapp 2015). The World Health Organization (WHO) defines dementia as a syndrome in which there is deterioration in memory, thinking, behaviour and the ability to perform everyday activities. The most distinguishable risk factor for dementia is age (Alzheimer's Society 2017, National Institute on Aging 2017, Gonzalez et al. 2014). Dementia is chronic, and non-communicable, progressing slowly until death, and is a main cause of disability and dependency as it impacts the psychological, social and biological aspects of an individual (WHO 2017).

## Approaches to Dementia and Care

In 1995, the clinical file and hand written notes by Dr. Alois Alzheimer were found of patient Auguste Deter, the fifty-one year old woman with early-onset dementia whose symptomology and pathology set the foundation for building the Alzheimer's disease framework (Whitehouse & George 2008). Today, Alzheimer's is considered the most common of various types of dementia, together with vascular dementia, Lewy body dementia and frontal-lobe dementia. Dementia symptoms can be caused by diseases such as Parkinson's, Huntington's disease, Creutzfeldt-Jakob's disease, and Multiple Sclerosis, as well as by brain damage from alcoholism, traumatic brain injury, AIDS, and toxic environments (Wisconsin Bureau of Aging 2003). The medicalization of dementia is credited by Whitehouse & George (2008) to Dr. Emil Kraepelin, Dr. Alois Alzheimer's mentor, who coined the term Alzheimer's disease for the first time in his 1910 psychiatry scholar manual, although, both Alois Alzheimer and his contemporary Oskar Fischer, a Czech medical doctor and dementia researcher, did not subscribe to a separate diagnosis from senile dementia (Goedert 2009, Whitehouse & George 2008, Innes 2009). The labelling of dementia as a disease defined it as a medical problem, deviant from a normal brain aging process, needing treatment and cure (Bond 1992, Whitehouse & George 2008, Goedert 2009, Innes 2009).

In a macro context of changing demographics and social rights movements, the second half of the 20<sup>th</sup> century roused psychologists and sociologists to analyse and reform the framing of dementia and the provision of care. The evolution of the theoretical framing of dementia began with the authoritative, positivistic biomedical model, the foundation for medical care stemming from the natural sciences. Then mid to late 19<sup>th</sup> century social constructivist theories brought to the forefront previously unexplored, abstract attributes of health, such as personal experience, and psycho-social contexts. This evolution incited the perspective that the interactions between all of the dimensions of an individual: the biological, psychological, social, spiritual, and environmental dimensions, affect the individual's health, and that dementia care models need to take the whole person, those interactions, into consideration.

Through this perspective, I chose the biopsychosocial model of health to frame this study. As will be described in this section, this model encompasses the main elements of the other approaches in framing dementia. The common thread of the approaches, with the exception of the biomedical, is that health is the sum of the interactions between an individual's various dimensions. This is the guiding principle of the biopsychosocial model. Therefore, I use the biopsychosocial model as the representing paradigm in understanding dementia and structuring dementia care.

In this section, I provide a brief summary of each approach to dementia in chronological order of development or application to dementia: biomedical, person-environment fit, biopsychosocial, ecological, social model of disability and psychosocial; to highlight how the interactions between dimensions have been validated as essential for the care of a person living with dementia. I concisely describe spirituality as an additional dimension commonly included implicitly in the psychological domain of the approaches, and, I interpret the holistic approach. Lastly, I discuss the person centred approach to framing models of dementia care.

## The Biomedical Model

Stemming from Descartes' (17<sup>th</sup> century) philosophy of dualism, the separation of mind and body, the biomedical perspective is an "epistemological tradition [of] cultural and historical construction (...)" (Scheper-Hughes & Lock 1987, p7). The focus on disease as external to the individual and being measurable and objective derives from biology and is positivistic in that illness exists independently of an individual. According to Engel (1977) Christianity played a principal role in maintaining the mind and soul a religious domain, and by permitting dissection of the human body, sustained dualism, the idea of the body as a vessel not connected to the mind or behaviour. Cartesian dualism is a reductionist view of the body, as only mechanical systems and the mind, rational thinking and emotions, as separate (Owen & Holmes 1993, Tjale & Bruce 2007, Borrell-Carrio et al. 2004). Through this lens, dementia has been socially constructed as a

biological disease, an epidemic, prompting pharmaceutical treatments for dementia, ageing and death (Whitehouse & George 2008, Innes 2009). The subjective experience and the influence of the observer are ignored (Whitehouse & George 2008, Innes 2009, Engel 1997). Four main elements of medicalization have been outlined by Bond (1992, p400):

1. Expert control is the monopoly of knowledge regarding disease, its diagnosis and treatment by medical professionals
2. Social control is also under medicine's hat by way of establishing the criteria and procedures of being labelled as having deviant behaviours, having dementia, and of granting social status
3. Individualization of behaviour holds the individual responsible rather than society as a whole, as seen in the disability model (Swain & French 2000, Oliver 1998), where the individual is disabled because they cannot function in the environment which is unfriendly, yet it is the individual that must adapt not the environment
4. Depoliticization of behaviour defines dementia as a disease thus appropriates behaviour to the disease rather than searching for individual contextual explanations, or root causes such as pain or need to communicate.

These four elements can be found in the concept of population health. Population health, or public health, was developed based on the biomedical model, where collective social action produced social hygiene regimes and the organization of medical care (Porter 1999). A public health motivated movement in dementia is the drive for diagnosis that boasts benefits such as: empowerment of people, facilitating autonomy, allowing planning plus acting as a catalyst for discussions about Power of Attorney, maintaining health, driving vehicles, advanced care planning, and preventing crisis situations, (Burns and Buckman 2013, Fox et al. 2013). Many of these benefits are also derived from psycho-social approaches that frame them as rights, as will be explained subsequently.

Another side of the public health approach to dementia is the current social movement toward prevention and control through media marketing of fear, en masse prognosis, estimated prevalence and incidence rates, and distribution of

feeble evidence based drugs (Whitehouse & George 2008, Innes 2009, Bond 1992, Lyman 1989, Sabat 2019). Critiques of this biomedical approach begin with the shortcomings of diagnosis, understated in the literature: that “there are no features within the brain that can be reliably said to ‘cause’ the dementia syndrome” (Fox et al. 2013, p.e510), the setting of expectations of effective albeit inexistent treatments, and absent quality research evidence for pre-symptom diagnosis, and the negative stigma (Fox et al. 2013, Sabat 2019). Another element of criticism points to the focus on biological research, where direct biological causality of dementia symptoms is “incompatible with clinical observations” (Iliffe and Manthorpe 2017, p344). Additionally, the alarmist biomedical marketing of dementia spurs critique from families living with dementia who feel that the focus on loss, decline, and decay is not consonant to their lived experiences (Gaugler et al. 2019, Sabat 2019). Through this biomedical lens, the person living with dementia is viewed as consisting only of disease. The individual’s biological dimension is the focus, while the effects of dementia on the individual’s other dimensions remain unacknowledged.

## Person-Environment Fit Theory

The person-environment fit (P-E fit) theory recognizes the important role the environment plays in an individual's health. The interactions between an individual and their environment contribute to the individual’s health through aspects of familiarity, control, security, and stimulation. The person-environment fit (P-E fit) theory was first conceptualized by Lewin in 1951 whose definition of a person’s environment included the person, the physical space and the psychological space in which interaction took place. The individual’s psychological space was developed further by Lawton and Nahemow in 1972 into competence to meet environmental demands (Phillips et al. 2010). The interaction between individual and environment involves adaptation (Nahemow and Lawton 1973) and competencies such as cognitive functioning, biological health and sensory motor skills or functional capacity (Iwarsson 2005).



Where the biomedical model concentrates on measuring objectivity, the P-E fit model opens the doors to subjectivity and individual needs (Iwarsson 2005, Phillips et al. 2010, Lawton 1972). Possibly the basis for Finkelstein's (1980) and Oliver's (1998) social model of disability, described subsequently, the P-E fit model points the finger at society which builds environments aimed at younger people whose functional capabilities will eventually change.

The P-E fit model provides four possible personalizable 'treatments' to offer an individual greater control over his environment (Lawton 1972):

1. Individual initiation – applied to individual: active pursuit of goals with acknowledgment for need of personal change, high personal and interaction competence levels.
2. Individual initiation – applied to environment: modification of one's own environment adapting it to one's competence maintains power, dignity and social citizenship (Bartlett 2007).
3. Individual responds to individually applied treatment: health and social care professionals' provision of individual therapy assisting to increase levels of individual competence in order to adapt to the environment.
4. Individual responds to change applied to environment: redesign of physical and social environments to satisfy a wide range of human needs rather than just aesthetics.

These 'treatments' highlight how environments must be modified to meet an individual's changing needs, and how the interactions between individual and environment are dynamic.

Specifically for dementia care settings, Lawton et al. published the Professional Environmental Assessment Protocol (2000). It evaluates eight essential environmental domains: safety and security, awareness and orientation, support of functional abilities, facilitation of social contact, privacy, opportunities for personal control, promotion and regulation of high quality stimulation and encouragement of continuity of identity of self (Barnes 2002). These eight domains articulate the diverse aspects of a complex environment that incorporates many facets of the approaches to follow such as socialization, selfhood, person centred care, individual rights and dignity.

The P-E fit theory underlines the capacity of the environment to affect an individual's competence, physical and psychological. The validity of the interactions between the environment dimension and the physical, or biological, and psychological dimensions is clear.

## Biopsychosocial Model of Health

The biopsychosocial model of health offers a multidimensional understanding of the factors affecting an individual and illness, and the interactions among those dimensions. Where many argue that the biomedical model dehumanizes and disempowers individuals, the biopsychosocial model (biopsychosocial) aims to highlight the underlying interactions of human dimensions offering a medical practitioner the framework to build a relationship with a patient (Borrell-Carrio et al. 2004, Engel 1977, 1981, 1997, Keady et al. 2012). Engel proposed the 'new medical model' in 1977 making the consideration that medicine was insufficiently meeting its social responsibilities by conforming to an inadequate model of disease. He argued in the same article, that the primary data for identifying disease have historically always been behavioural, psychological and social. "The boundaries between health and disease (...) are diffused by cultural, social and psychological considerations" (Engel 1977, p196). Through this model, health is viewed through interconnected systems, bringing to mind the five systems in the ecological model, which I will describe next. The focus on disease is the biological system; evaluation of thoughts, emotions, and feelings is the psychological system; and the social context of an individual is the sociological system, all of which incorporate respective environments (Keady et al. 2012, Engel 1977, Papadimitriou 2017). Engel desired to give patients a sense of being understood, and to do so believed in a system that attended to the biopsychosocial dimensions of disease concurrently (Borrell-Cario et al. 2004).

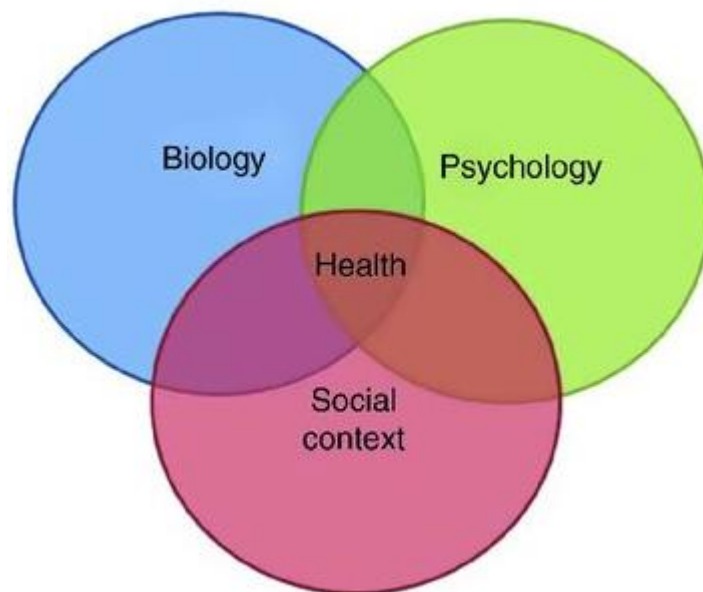
The application of the biopsychosocial model has been proposed to deliver holistic care, a concept I will discuss successively (Borrell-Carrio et al. 2004, Keady et al. 2012) and has been supported by the dementia care community. Spector and Orrell's (2010) analysis concluded biopsychosocial to be a theoretical framework

inclusive of both positive and negative factors. Revolva et al. (2016) performed a pilot study using the biopsychosocial model as a tool for clinical dementia practice with positive staff reports on improved understanding of the three systems. Iliffe and Manthorpe (2017) vindicate the model's relevance to dementia indicating it may lead to a triad of impairments. Sabat (2008, p82), developer of selfhood theory described subsequently, declares "the biopsychosocial approach is required for understanding people with dementia and for the further evolution of good practice in supporting people to live well with dementia" and it incorporates selfhood into the psychological system of biopsychosocial.

Criticism of the model from the psychiatry community claims personalization of treatment leads to professional eclecticism, where it is the medical practitioner's choice which system to focus on (Ghaemi 2009). According to Keady et al. (2012, p2768) adding a physical domain to the biopsychosocial model would constitute a "holistic and culturally sensitive approach". Supporters refuting this latter criticism claim the physical domain to be included in the biological dimension (Gatchel et al. 2007), and in reply to the former, the choice is irrelevant if the fundamental idea of the model, interactions between dimensions, is maintained.

Reiterating, the biopsychosocial model (Figure 2) opposes the assumption that mental and social phenomena can be reduced only to biological occurrences, and ascertains the underpinning of interactions between and among the three systems in the diagnosis and treatment of illness (Borrell-Carrio et al. 2004, Keady et al. 2012, Engel 1977, 1980, 1997). As aforementioned, this model of health frames this study on the basis of its application to the understanding of dementia as a multifaceted condition, affecting multiple dimensions of an individual, and thus leading to a multidisciplinary approach to care.

Figure 2 Biopsychosocial Model of Health



The subsequent descriptions of further approaches serves to provide an exhaustive consideration of understanding dementia and framing care, and to elicit the various intricate interactions that are implicitly encompassed by the biopsychosocial model.

### Ecological Systems Theory of Health

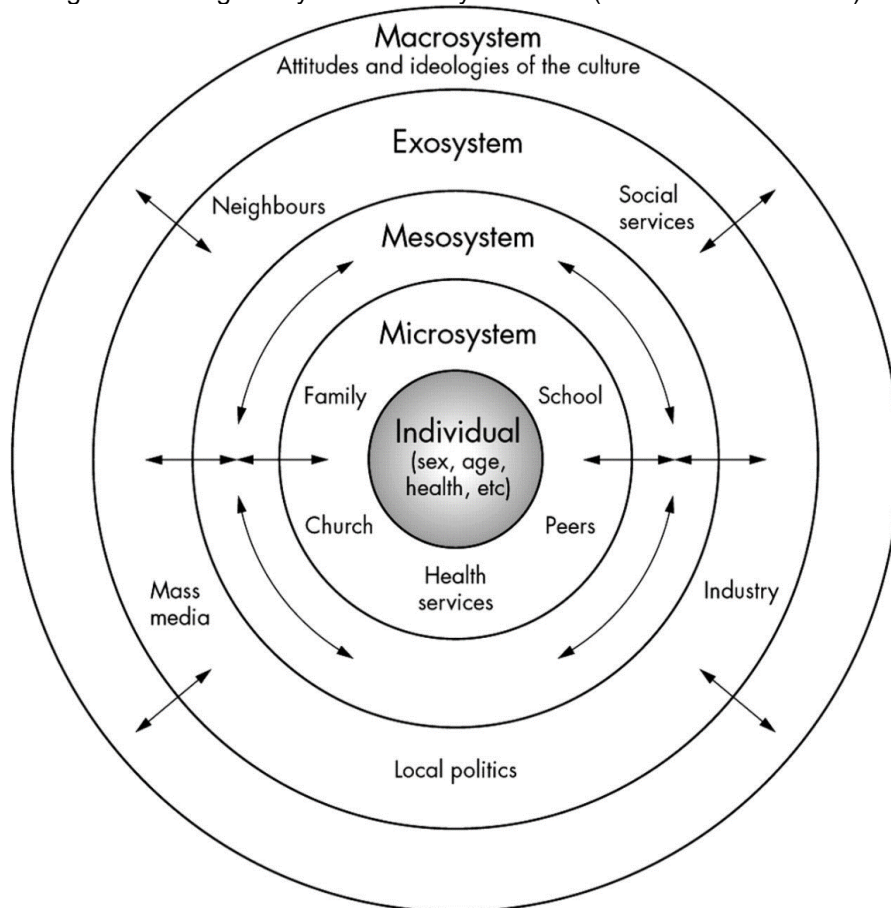
The entire ecological system is taken into consideration to understand the development of an individual, applied through growth and/or through disease, according to Bronfenbrenner who developed the ecological model in 1977 (Bronfenbrenner 1994, 1999, Moore 2014, Calkins 2001, Schiamberg et al. 2011, Schiamberg and Gans 2000). Bronfenbrenner (1977 p.514) defines the ecology of human development as:

“The scientific study of the progressive, mutual accommodation, throughout the lifespan, between a growing human organism and the changing environments in which it lives, (...) this process is affected by relations (...) within and between these settings (...).”

Five nested systems make up an individual’s ecological environment: the micro system is the immediate environment; the mesosystem involves major social

settings; the exosystem includes essential social structures; the macrosystem comprises overall institutional patterns of culture; and finally the chronosystem accounts for temporality and changes through the life course (Figure 3). As aforementioned, this system approach recalls the biopsychosocial model, where a system is multi-faceted and inclusive of interactions within and among other systems, that make up an individual's health (Bronfenbrenner 1977).

Figure 3 Ecological Systems Theory of Health (Bronfenbrenner 1977)



The ecological model has been adapted in the design of environments of people with dementia and in the analysis of interactions resulting in abuse in nursing homes (Calkins 2001, Schiamborg et al. 2011, Schiamborg and Gans 2000). In both types of evaluations, variables and interactions are viewed across systems acknowledging, according to Calkins (2001), a more holistic strategy of examining dementia care settings.

Any system of a complex environment can either be a barrier or a facilitator to quality of life for people living with dementia (Calkins 2018). Recalling the Person-Environment fit theory, the ecological model emphasises the vital role that the interactions between an individual and their environments have on an individual's ever-changing health.

## Social Model of Disability

The divide between disabled and non-disabled people is fundamentally based on perceptions and experiences (Swain & French 2000). It is not that one group has impairments while the other group does not, nor is it that one group is oppressed and the other is not, because both of these premises can be debunked.

Farsightedness is an individual impairment, yet not socially considered a disability. Non-disabled persons may be oppressed by other characteristics such as poverty, race, religion, sexual orientation. Disability is defined as an oppressive social relationship (Finkelstein 1980), and the social model of disability explains disability as caused by social restrictions and barriers (Oliver 1996, 2013). An individual model of disability stems both from the positivistic theory of searching for a cure and labelling an unemployable individual as disabled in order to receive government support. On the opposite pole, the social constructivist theory builds on the personal experiences of disabled people, which can be a slippery slope to sympathetic biographies or personal tragedies (Shakespeare & Watson 1997, Swain & French 2000, Finkelstein et al. 1993). The social model of disability began as a social movement, an association of disabled people founded by Finkelstein in the 1970s and later developed as a theory by Oliver in the 1990s. It was born out of the personal experiences of disabled people, challenging the medical, individual models, defining the problem not as the impairment but how society hampers and regulates a person's participation and functioning via the environment and oppression (Shakespeare & Watson 1997, Oliver 1998, 2013, Swain & French 2000, Finkelstein et al. 1993, Finkelstein 1980). "Disability is something imposed on us on top of our impairments (...)" (Finkelstein 2007, p2). The link to dementia is fundamental in moving the focus from requiring an individual to change, to developing dementia friendly communities, services and policies that deal with the impact symptoms of dementia cause (Williamson 2015,

Mental Health Foundation 2015). Applying the social model of disability to dementia reveals the roles society, the environment, and interactions play in people's experiences of living with dementia (Dorenlot 2005, Gilliard et al. 2005). Diagnosis or being aware of an impairment is an important aspect of this model, where in dementia it is ambiguous and prognostic which is a barrier to an open discussion about needs, services and the future (Gilliard et al. 2005). Thomas' (2004) revised definition of disability as a social restriction of activity or socially induced undermining of wellbeing, distances the biological view of impairment and emphasizes the value of interactions between the individual and his/her environment, reiterating the theme of interactions underpinning the aforementioned biopsychosocial, P-E fit and ecological models.

## Psycho-Social Models

In an effort to migrate from the biomedical model and broaden the lens for understanding dementia and providing care, the wider context of an individual is considered to explain symptoms like behaviours, bio-medically and neuro-psychiatrically labelled deviant (Kitwood and Bredin 1992, Kelly 2010, Innes 2009). "It is a question of not just medication but the whole business of living a meaningful and enjoyable life - with support systems, community, self-respect, and being respected by others - which has to be addressed" (Sacks 2015, p63). Three principle psychosocial approaches revolutionized policies and the provision of care for people with dementia: personhood, selfhood and social-citizenship. "The focus of treatment in a psychosocial model of dementia care is the person" (Taft et al. 1997, p14). From these, therapies and approaches were developed, predominantly in the United States, outlining best practices especially designed for institutional care such as Validation Therapy by Feil (1982), The Eden Alternative by Thomas and Meyer-Thomas (Eden-Alternative 1991) and The Best Friends Approach by Bell and Troxel (1996).

Personhood was first applied to dementia care by Kitwood (1992) and has become a commonplace concept in the general field of aging (Brooker 2003). Dewing (2008, p3) offers a general definition of personhood as "the attributes possessed

by human beings that make them a person". Personhood is interpreted and applied through different perspectives depending on individuals and contexts, thus lacks one consensus definition (Epp 2003). The four main themes according to Brooker (2003) are:

1. Valuing people with dementia and their carers
2. treating people as Individuals
3. considering the person with dementia's Perspective
4. providing a positive Social environment to experience wellbeing.

VIPS is the acronym Brooker uses to indicate the four themes, mirroring the renowned acronym for very important persons, to underline how people living with dementia should be treated.

Epp (2003) summarizes three techniques to foster Kitwood's idea of positive interactions to maintain personhood: validation, holding, and facilitation. Bartlett and O'Connor (2007, p109) sustain that personhood gave back life and voices to people with dementia opposing descriptions of "the death that leaves the body behind" and promoting the value of personal experience. They also indicate that this concept denoted the consequences of a person's interactions with their social and physical environment as paramount to their experience of dementia. Criticism of the approach includes faulting personhood for focusing on social interactions, ignoring the expression of self that continues with dementia (Kelly 2010) and that the abstractedness of the concept and the insufficient framework thwarts practice or application of personhood (Epp 2003, Higgs and Gilleard 2016). In addition, there seems to be agreement in critiquing personhood for shifting the blame from the disease, the biomedical perspective, to the immediate environment, still maintaining a sense of self-responsibility rather than observing the influence of wider socio-political structures (Bartlett & O'Connor 2007, Taft et al. 1997, Innes 2009). Personhood is the underlying concept of person centred care, and is expressed, according to interviews of people living with dementia and their families (Milte et al. 2016, p11), through a maintenance of: choice, freedom and self-determination; meaning-ful activities; feeling useful and valued, and respect for personal possessions and space. These elements are also affirmed in the concepts of selfhood and citizenship through the principle of interactions.



In 1992, prompted by a book entitled *Alzheimer's Disease: The Loss of Self*, Sabat and Harrè (1992) explored the nature of the self via a social constructivism perspective. They sustained that the qualities of social interactions and their interpretations influence the view others have of the person with dementia, the self of the person with dementia is not lost (ibid). Selfhood provides a framework which includes three selves: *self 1* is the self of personal identity, personal pronouns, having a single point of view; *self 2* is the combination of physical, emotional, mental aspects and beliefs; *self 3* is the variety of public or social identities that we present when interacting with others, the behaviours and how we express our multiple roles (Sabat 2005, Kelly 2010, Sabat & Harrè 1992). With dementia, *self 3* is defined, supported or extinguished through interaction with others. The personal identity, *self 1* remains intact, according to Sabat and Harrè (1992) through even severe cognitive impairment. Selfhood expresses how the interactions between the social environment and an individual living with dementia affect an individual on different levels of self.

Citizenship is another idea viewing the dynamic interactions of social structuring from a social psychological perspective, based in political theory. Giving power to people with dementia is a key element of the citizenship perspective, which is connected to the disability and rights movement. It is an empowerment of individuals to improve their status and treatment by defining their own identity, recognizing differences, and actively participating in the shaping of society (Bartlett & O'Connor 2007). Citizenship is an active and fluid state or practice, "meaningfully constituted in interaction", an imaginary identification established via discursive action (Barnes et al. 2004, p189). Rights and obligations are intertwined within the concept of citizenship and it has become a central theme in disability theories. According to Bartlett and O'Connor (2007), citizenship changes how behaviours of people with dementia are acknowledged, from symptoms of a disease, to exercises of power, and means of communication. Through interactions between an individual and society, the identity of an individual living with dementia is moulded. The association Dementia Action Alliance is an example of people living with dementia taking citizenship through advocating for

their own rights, power and voices in social structures such as participation in conferences and in policy co-design.

## Spirituality

Another psychosocial concept associated with personhood, selfhood, and citizenship, is spirituality. Jolley and Moreland's (2011) literature review finds a consensus definition of spirituality as a process of seeking and/or finding meaning and purpose in life. Although not mentioned independently, the concept of spirituality can be interpreted as a distinct dimension of an individual's health, or a facet of the psychological system of the biopsychosocial model or of a system of the ecological model. According to Page (2007), it is an intangible concept with many definitions; she cites spirituality as the universal need for purpose, values, relationships and wholeness. In a study by Carr et al. (2011) acknowledgment of the little things was identified as spirituality by persons with dementia: those intentional acts of caring, sustaining the preferences of a person and promoting meaningful and mutual exchanges, related with a sense of being cared for, loved and comforted especially with impaired communication of needs. Dementia is progressive and with or without comorbidities accompanies a person to the end of life, a stage of palliative and hospice care, which models' of care have consistently provided attention to the spiritual needs (Sulmasy 2002). It is worthy to note that in the literature the spirituality concept is not bound to religion or faith as a necessary or only channel. It is inter-related to the health of an individual and it is respected and cultivated through holistic and person centred approaches to care.

## Holistic Approach to Care

Holistic care is an ubiquitous term in the literature. Classified as the opposite pole to reductionist, (Engel 1977) holistic stems from holism, from the Greek holos, whole. The concept of holism was theoretically posited by Jan Smuts in 1927 as:

“A structure or synthesis and arrangement of parts, cooperative, coordinated into relations and functions to preserve and maintain activities. [In the human specific case the structural synthesis has] the brain as the

element of control and direction, and the highest flowering of the central control in the human is the personality.”

“Holism has been likened to trying to hold ice” (Owen and Holmes 1993). It is an ambiguous term with no agreed upon definition (Jasemi et al. 2017). The biopsychosocial model is considered as the foundation of modern holistic care (Tjale and Bruce 2007) and a literature review by Jasemi et al. (2017) found the concept of holistic care used interchangeably with person centred care. The characteristics of holistic care may eventually lead to a delineation of the concept, and according to Frankl (1984) motivate an individual in his search for meaning. Mind, body, spirit, whole, harmony and healing were the features found in a concept analysis by McEvoy and Duffy (2008). Nursing is described as a profession regarding the whole person where the elements of the whole person are physical, mental, emotional, and spiritual (Tjale and Bruce 2007). A more recent literature review combined with nurse narratives defines holistic care as enabling full recovery through a thorough style of care addressing the individual’s full needs (Jasemi et al. 2017).

The broadness of the holistic approach attracts criticism on the grounds of the impossibility to consider the entirety of an individual’s aspects and experiences, and that any event is always explained as relative to the whole. In addition, even minimal standardization is abstained because the holistic lens is used to understand the individual case (Owen and Holmes 1993). Advocates supporting the value of considering the spiritual dimension in general health care promote a holistic environment. Specific to dementia, Iliffe and Manthorpe (2017) advise to deter the over concentration on dementia as a separate essence by specialists, through a holistic approach. Sulmasy (2002, p26) describes "a system of health care that attends to all of the disturbed relationships of the ill person as a whole, restoring those that can be restored even if the person is not thereby completely restored to perfect wholeness" as holistic care. This vision connects with the biopsychosocial model in promoting interconnectedness of an individual’s multiple dimensions and person centredness by way of acceptance of irreversible change.

## Person Centred Care

Person centred care is the practical embodiment of the personhood, selfhood, and citizenship approaches to understanding dementia and as aforementioned incorporates spirituality. It is based on the assumption that the social, psychological and cultural dimensions need to be included in an approach to care (Doyle and Rubenstein 2013), endorsing the biopsychosocial model. The key idea, developed by Kitwood (1993), was that an individual's entirety constituted elements pertinent to their wellbeing, thus care techniques must recognize the person as valued and worthy, and capable of understanding and making choices. The application of this perspective in providing care to people living with dementia has led to the development of a variety of tools and frameworks suggesting what elements constitute a person centred approach.

A 2010 review of published tools designed to provide measures of the implementation of person centredness in care directed at older adults and people living with dementia (Edvardsson and Innes), discovered 12 instruments, with one focused on dementia care. The scope of elements measured ranged from observation of people living with dementia and evaluation of the care setting, to subjective perception of care staff, families and persons living with dementia. From a macro perspective, in a 2016 study, the international charity the Picker Institute compared five European countries' strategies of implementing person centred care outlining the key components to be:

- Fast access to reliable health advice
- Effective treatment delivered by trusted professionals
- Continuity of care and smooth transitions
- Involvement of, and support for, family and carers
- Clear, comprehensible information and support for self-care
- Involvement in decisions and respect for preferences
- Emotional support, empathy and respect
- Attention to physical and environmental needs

In 2016, the World Health Organization published the Framework on Integrated People Centred Health Services, which included five guiding strategies:

1. Empowering and engaging people and communities
2. Strengthening governance and accountability
3. Reorienting the model of care

4. Coordinating services within and across sectors
5. Creating an enabling environment.

Through a macro lens, the link between person centred care and integrated care is visible, moving from applying the person centred approach to the care of individuals, to designing care systems that facilitate and guarantee that person centredness, The movement to measure the practice of the approach, and the leap from micro to macro, both marked the meeting of the positivist and interpretivist minds. Where the care of personhood becomes measurable, a critical realistic stance is taken, as explained in the next chapter.

## Conclusion

The biomedical model continues to prevail (Gilliard 2005). It remains the general foundation of how dementia is conceived, as a recent example demonstrates:

“Dementia is a devastating and progressive illness that results in the loss of one’s sense of self and feelings such as frustration, depression, and anxiety” (Goldstein-Levitas 2016, p429).

This inevitably impacts what care services are developed and how they are organized. Psychosocial approaches set the standard that care of the person with dementia must recognize the continued existence of the person, and the significance that a sense of security and love foster spirituality in the face of cognitive and physical deterioration (Carr et al. 2011). As Sacks described, “[they] need(ed) meaning - a life, an identity, dignity, self-respect, a degree of autonomy [which] was ignored or bypassed; ‘care’ was purely mechanical and medical” (2015, p223). The environment, as subscribed to by Lawton and Nahemow’s P-E fit model (1973) and Bronfenbrenner’s ecological model (1977), also encompasses what the psycho-social frameworks state explicitly, the validity of the interactions between the various dimensions of an individual, personal history and personality, and the social-environmental contexts.

The theoretical evolution has honoured the philosophical dissonance with the biomedical model, the idea that the human being is in a relationship (Sulmasy

2002). The biopsychosocial model provides the needed framing of dementia which entails collaboration between biomedicine, psychology, and social sciences (Portacolone et al. 2014) and embodies both the positivistic biomedical and the social constructivist psychosocial approaches to care. In the following section, another evolution is illustrated, of the international policies protecting older adults, which led to specific policies supporting the rights of people living with dementia.

## International Ageing and Dementia Policy

Dementia policy is a relatively new field (Wortman 2012), thus a brief history of global dementia policies is provided, and from this, a mapping was created of the international organizations involved (Figure 4). In this section, I will describe the main organizations, which lead world policy making and their participation in shaping dementia policy.

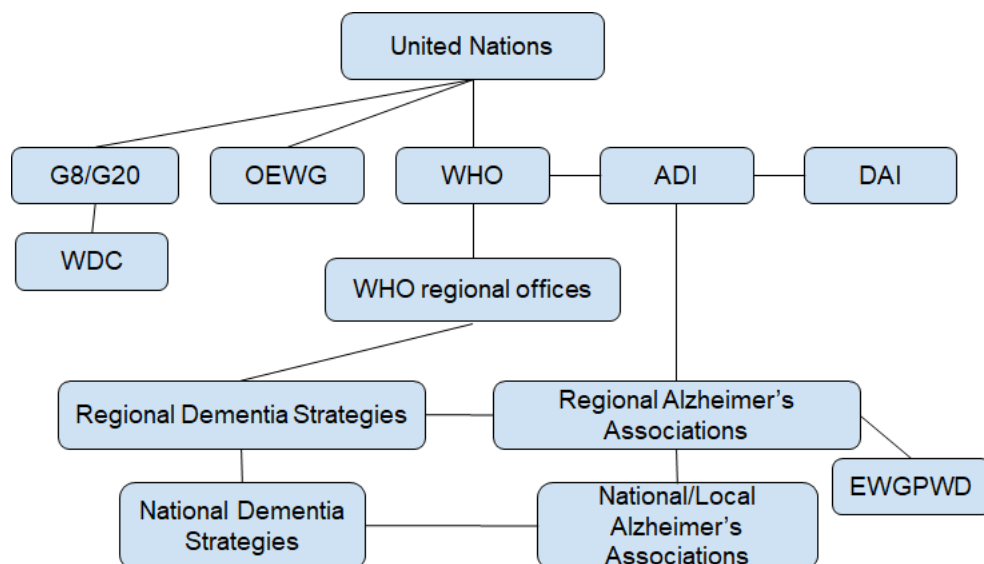
The history and evolution of older adult and dementia policies illustrates the inception on an international level, of a political stance for the protection of the rights of older adults and specifically people living with dementia. Policies are the foundation for services and provide parameters for adherence to protecting the rights and needs of families living with dementia (Rosow et al. 2011). As will be described in subsequent sections and in the discussion chapter, policies allow for the structuring and coordination of dementia service systems.

United Nations' charters, conventions and plans provide a framework of rights and responsibilities. The United Nations (UN) is an international organization founded in 1945. It is currently made up of 193 Member States. The promotion and protection of human rights is a key purpose and guiding principle of the United Nations. Within the Secretariat of the UN, the Human Rights Council is an inter-governmental body responsible for strengthening the promotion and protection of human rights around the globe and for addressing situations of human rights violations and making recommendations on them. It has the ability to discuss all thematic human rights issues and situations that require its attention throughout

the year. The Human Rights Council is made up of 47 United Nations Member States, which are elected by the UN General Assembly. The Human Rights Council replaced the former United Nations Commission on Human Rights.

The UN organized the first World Assembly on Ageing in 1982, which produced the Vienna International Plan of Action on Ageing. It contains 62 guidelines and recommendations that “should result in societies responding more fully to the socio-economic implications of the aging of populations and to the specific needs of older persons” (United Nations 1983). Almost a decade later, in 1991, the resolution United Nations Principles for Older Persons was annexed to the Vienna International Plan. It encouraged governments to incorporate eighteen principles, divided into Independence, Care and Self-Fulfilment, into their national programmes (UN Resolution 46/91). Following the first World Assembly, the Proclamation of Ageing was written by the UN General Assembly urging international cooperation and national ageing policy initiatives (UN Resolution 47/5 1992).

Figure 4 Global dementia policy making organizations



ADI: Alzheimer's Disease International  
 DAI: Dementia Alliance International  
 EWGPWD: European Working Group of People with Dementia  
 G8/G20: Global forums  
 OEWG: Open-Ended Working Group on ageing  
 PAHO: Pan-American Health Organization  
 WDC: World Dementia Council  
 WHO: World Health Organization

The second World Assembly on Ageing took place in 2002 and produced the Madrid International Plan of Action on Ageing. This plan was divided into three primary areas to help Member States develop and implement policies on ageing: to promote health and well-being into old age, the design of national policies and programs and to ensure and enable supportive environments (United Nations 2002, Guarini Institute 2002). Five years later, the UN published a report examining what steps had been taken in accordance with the Madrid recommendations. Results showed that many member states had developed special government offices or agencies, others had created councils representing and inclusive of older adults, and still others had adopted national plans on ageing (Butler et al. 2008). Four years after that report was published, in 2010, the United Nations' General Assembly established the Open-Ended Working Group on Ageing (OEWG). Its goals are to examine the existing international framework of the human rights of older persons and identify possible gaps and how best to address them. The most recent United Nations contribution to policy regarding dementia is the Non-communicable Diseases Political Declaration of 2012. In this political declaration was specifically recognised article 18, neurological diseases including Alzheimer's disease, as an important cause of morbidity (United Nations 2012). It was a major step in the public health approach to acknowledging dementia (ADI 2011). Table 1 illustrates the global dementia policy contributions and by which organization they were made.

Within the United Nations system, the World Health Organization is the directing and coordinating authority on international health (WHO 2020). The objective of WHO is the attainment by all peoples of the highest possible level of health. Health, as defined in the WHO Constitution, is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. The WHO provides leadership on an international level to governments and organizations, shapes research agendas, sets standards and guidelines, divulges ethical and evidence-based policy recommendations, provides technical support and monitors trends and development. The 194 member states of WHO are divided into 6 regional offices: the African Region, the Region of the Americas, South-East Asia Region, European Region, Eastern Mediterranean Region and the Western Pacific Region. Reports, reviews, and briefs are published and



forums and symposiums are organized by WHO and in collaboration with associations, institutions and groups such as ADI. In addition, the WHO often works on developing policies for governments in partnership with experts

Table 1 Older adult and dementia global policies

YEAR	ORG.	ACTION
2019	G20	Declaration: point 31 addresses dementia
2017	WHO	Global Plan on the Public Health Response to Dementia 2017-2025
2016	WHO	Framework on integrated people centred health services
2016	WDC	World Dementia Council Action Plan
2015	PAHO	Dementia Strategy
2015	WHO	Ministerial Conference on Global Action Against Dementia
2014	AE	Glasgow Declaration
2013	WHO	Mental Health Action Plan 2013-2020
2013	G8	Development of World Dementia Council
2011	UN	Non-communicable Diseases Political Declaration
2006	AE	Paris Declaration
2006	UN	Convention on Rights of Persons with Disabilities
2004	ADI	Kyoto Declaration
2002	WHO	Global Report: Innovative care for chronic conditions
2002	UN	2nd World Assembly on Ageing: Madrid International Plan of Action on Ageing
2000	WHO	Towards an international consensus on policy for long-term care of the ageing
1992	UN	Proclamation on Ageing
1991	UN	United Nations Principles for Older People
1982	UN	1st World Assembly on Ageing: Vienna International Plan of Action on Ageing

ADI Alzheimer's Disease International  
 AE Alzheimer's Europe  
 G20 Global Forum: EU+19 countries  
 PAHO Pan-American Health Organization  
 UN United Nations  
 WDC World Dementia Council  
 WHO World Health Organization

Both ageing and dementia are found on the WHO website in the health topics directory. The most recent policy publication on the dementia page, the Global action plan on the public health response to dementia 2017 - 2025, is intended to provide a set of actions with the aims of preventing dementia and providing care to families living with dementia. Concurrently, the Global Dementia Observatory was developed to monitor, review and exchange international, web based data on dementia policies, service delivery, and information and research.

In 2015, during the first Ministerial Conference on Global Action against Dementia five main themes were discussed:

1. Accelerating focus on dementia risk reduction
2. Strategic approaches for dementia research
3. Living well with dementia
4. Improving dementia awareness and reducing stigma
5. Strengthening global leadership and a call for action

More than 80 countries were present with ministers, experts in the field, and non-governmental associations, making it the largest meeting and recognition of dementia (ADI 2015). The same year, the Pan-American Health Organization (PAHO) which is the WHO's office for the Region of the Americas, published their Dementia Strategy. It is a 3-year plan of 5 strategic action lines:

1. Promote plans, policies, and programs
2. Establish interventions for prevention and quality
3. Implement a quality long-term care system
4. Develop or strengthen training
5. Improve research

The PAHO action plan faithfully represents the themes discussed in the Ministerial Conference. Most recently and for the first time, the G20 included dementia in their agenda (Alzheimer Europe, 2019) point 31 of the G20 final declaration (2019) states

"We will implement a comprehensive set of policies to address dementia, including promoting risk reduction and sustainable provision of long-term care as well as inclusive societies aiming to improve quality of lives of people with dementia and caregivers."

Alzheimer's Disease International (ADI) is the international federation of Alzheimer associations around the world. ADI has an official alliance with the World Health Organization collaborating to produce publications and achieve funding for Alzheimer's research (ADI 2020). Each member association is the Alzheimer association of a region, country or state, which supports people with dementia and their families. ADI's vision is prevention, care and inclusion today, and cure tomorrow. Europe and Latin America both have regional offices, and there are 104 country offices that branch out further into local chapter offices (ADI). The federation's principle mission is to support the associations and raise global awareness of dementia and the need for research. The individual associations'

roles are to bring together the many actors involved in dementia such as the person with dementia, the family, the carers, practitioners, and researchers, and to offer support and information. In addition, the associations advocate in their local communities and provide training. Similar to the World Health Organization, ADI develops reports and policy recommendations. The Kyoto Declaration (2004), presented at ADI's 20<sup>th</sup> anniversary international conference, was developed in collaboration with WHO and was an action plan for dementia. In 2006, at the Alzheimer Europe conference, Alzheimer Europe (AE) adopted the Paris Declaration on the political priorities of the European Alzheimer Movement. The declaration advocates for dementia to be given the political priority it requires from national and European policy makers and offers policy proposals (Alzheimer-Europe 2015). Also in 2006, the Convention on the Rights of Persons with Disabilities (CRPD) was written to protect people with disabilities' human rights (United Nations 2006). Laws on disability do not refer to dementia specifically (Mental Health Organization 2015) and Dementia Alliance International asserts that the CRPD must include people living with dementia. Together with Alzheimer's Disease International, they have recently proclaimed dementia to be recognized as an invisible disability (ADI 2015). Eight years later the Glasgow Declaration (2014) was launched and adopted by 26 AE member organisations. It called for the creation of a European Dementia Strategy and national strategies in every country in Europe as well as reiterated the need for dementia to be recognized as a public health priority and to develop a global action plan on dementia (Alzheimer-Europe 2014).

The other two leaders in dementia advocacy are both organizations of people living with dementia: The European Working Group of People with Dementia (EWGPWD) launched in 2012 by Alzheimer Europe and Dementia Alliance International (DAI), a U.S. registered not-for-profit corporation established in 2014. Members of EWGPWD are appointed by their national Alzheimer Associations and are all people with dementia. Dementia Alliance International (DAI) is also made up of individuals diagnosed with dementia and is in mutual association with the Alzheimer's Association. The aims of both are to provide collective support, advocate for the rights of people with dementia, and improve their quality of life

presenting concerns to professionals, organizations and governments. Compared to the Alzheimer's Disease Federation, neither EWGPWD nor DAI directly make policies; rather they consult with policymakers and provide feedback and recommendations. They provide a vital perspective of the people living with dementia and use the motto 'Nothing about us, without us' accordingly (EWGPWD 2019, DAI 2014).

The most recently formed international dementia organization is the World Dementia Council (WDC). The WDC was established after the 2013 G8 meeting. It is made up of 24 members, from six continents, of the global dementia community including researchers, academics, non-governmental organisations, industry, regulators, public sector and people living with dementia. The WDC's goal is to identify a cure or a disease-modifying medicine for dementia by 2025. The WDC also does not directly make policies, but its role is to coordinate the global effort and ensure priority is given to dementia in political agendas.

Alzheimer's Disease International, Dementia Alliance International and the European Working Group of People with Dementia in parallel with the World Health Organization, the World Dementia Council, and the Open-Ended Working Group on ageing, all support research and co-publish reports with evidence-based recommendations for policymakers of the United Nations to motivate regions and individual nations to confront the needs of people with dementia.

## National Dementia Plans

Parra et al. (2018) put forward the actions needed for Latin American countries to confront the increasing incidence of dementia. One action was for countries to endorse national and regional dementia plans.

A government dementia plan is a written document for the basis of action of a national or sub-national government holding itself accountable for the accomplishment of specific objectives and policy changes (ADI 2020, WHO 2018). Rosow et.al. (2011, p616) define a national plan as a "societal recognition

expressed either by the government alone or in combination with a national advocacy community that national health policy changes are needed to care and treat individuals afflicted with dementia, prevent or mitigate future cases of illness, and provide support to patients' caregivers". Strategies for planning the management of dementia care are non-legally binding documents developed by private non-governmental groups, but are also important because they provide information and recommendations to policy makers (ADI 2014). Jones (2014) claims that a national dementia plan may act as a central hub in coordinating support for health care workers and caregivers. Plans help ensure that governments structure health and social care systems appropriately and allocate enough funding to provide quality care (Pot and Petrea 2013). A national dementia plan is a country's best practice policy of programs to handle the new social and health challenge, similar to the organized national efforts on AIDS and diabetes, to meet the distinctive cultural and geographical needs (Wortman, 2012). Government dementia plans can promote the creation of infrastructure and accountability necessary to build dementia-capable programmes for the growing incidence (ADI 2014). Furthermore, the aims of planning dementia policy need to be in parallel with policies on health across the life course thus focus on a social public health approach (Wu et al. 2014, Kellehear 2009). This approach includes evaluating issues of support and services for people with dementia, promoting education on dementia to decrease the stigma and analysing prevalence and incidence. Alzheimer's Disease International (ADI) leads the effort in creating and supervising the development and implementation of national plans. According to ADI, to change dementia care and support, national dementia plans are the single most powerful tool (Pot and Petrea 2013).

The current guiding framework publications for national dementia plans are three published by the WHO and ADI. The WHO (2017) publication the Global action plan on the public health response to dementia 2017-2025, recommends 7 action areas, which national governments should include in their plans:

1. Dementia as a public health priority
2. Awareness and friendliness
3. Risk reduction; diagnosis
4. Treatment, care and support

5. Support for dementia carers
6. Information systems for dementia
7. Research and innovation

In response to the publication, ADI (2018, 2019) published two consecutive progress reports entitled From Plan to Impact I and II, stating that targets set out as global actions in 2017 would not be met by 2025. Within the report, ADI provided key themes and/or objectives to be included in national plans:

1. Awareness and education
2. Risk reduction
3. Timely diagnosis and access to treatment
4. Support at home, and for family carers
5. Coordination of care, including community care
6. Training for health professionals and service providers
7. Human rights, disability support and enablers
8. Dementia friendliness
9. Commitment to research

In 2018 WHO published the Towards a Dementia Plan: a WHO guide, a manual providing checklists, tips and indications to assist governments in preparing the groundwork for developing national plans. The guide reiterated the seven cross cutting principles underlying the global dementia action plan, to be considered national ethical aspirations:

1. Empowerment
2. Human rights
3. Equity
4. Universal Health and Social Care
5. Multisectoral collaboration
6. Attention to prevention, cure and care
7. Evidence based practice

Acting as nudges to national governments, the above publications advance dementia care onto the international forum, reminding policy makers to set standards of protection and quality.

Currently 32 countries, of 193 worldwide have adopted dementia plans, and ADI assessed that 28 new plans were being developed in 2018 (ADI 2018). Figure 5 shows the Latin American scenario. Of those 32 listed on the ADI website (2020), 6 are developing countries, of which 4 Latin American, 2 Asian (Mexico, Chile,

Cuba, Costa Rica, Indonesia and Qatar). The remaining 26 countries are developed countries mostly European, and Australia, Japan, and USA.

Figure 5 Latin American countries with a national dementia plan (ADI 2020)



The low number of developing countries with a dementia plan may be linked to the very little research that has been done in the low and middle-income regions to support policy making for people with dementia (Prince 2008).

Although historically there has been little government policy on dementia (Innes 2002), international awareness and outputs are steadily increasing as described. In the above-mentioned three frameworks provided for developing national dementia plans, a common thread emerges. Driving criterion for policies parallel components of the biopsychosocial model of care, e.g.: treatment, care and support; human rights, disability support and enablers; and empowerment. The criteria are also elements of integrated care such as: information systems for dementia; coordination of care; and multisectoral collaboration. The consensus that elements of the biopsychosocial model of health and of integrated care are essential to a national dementia plan first confirms the relevance of both concepts and that the two are linked, as will be developed in the next section. Furthermore, the above mentioned policy frameworks, joined with the key concepts of the biopsychosocial model of health, person centred care, and the integrated care philosophy, are all assembled into the Framework on Integrated People-Centred

Health services, (WHO 2016), which introduces the next section on integrated care.

## Integrated Care and Integration

In this section, the association between health system integration and integrated care will be discussed linking back to the framing of dementia discussed in the previous section. Integrated care is the implementation of the biopsychosocial model of health where the multidisciplinary interactions established as essential to health are manifested through the integration of the system of services.

The installation of the Framework on Integrated People-Centred Health services, (WHO 2016), was “a call for a fundamental shift in the way health services are funded, managed and delivered” (WHO 2020). Five key interdependent strategies structure the framework, and sustain the enduring movement of integration:

1. Empowering and engaging people and communities
2. Strengthening governance and accountability
3. Reorienting the model of care
4. Coordinating services within and across sectors
5. Creating an enabling environment

The movement toward integration was already underway in the 1990s as public sector and not for profit organizations were favouring cooperative alliances to increase effective outcomes (Provan and Milward 1995). In the literature, integrated healthcare is found to have a variety of different concepts and methods of application (Strandberg-Larsen and Krasnik 2009). Leutz (1999) suggests that in a health system, factors such as access to services, coordination, costs and bridging and crossing systems can be addressed by integration. The WHO (2000) defines a health system as comprising all of the organizations, people and actions, and whose primary responsibility is to promote, restore or maintain health. Browne et al. (2007) label an alliance of organisations providing people with services as a human services network: "a coalition or strategic alliance between appropriate agencies from multiple sectors (...) that collaborate and function to



provide a continuum of services (...)" Human service organisations aim to change negative social situations in collaboration with professionals or using a network approach, and to achieve success, Beatá (2013) claims networking or cooperation must be present.

Yet the division between health and social care is noted (Bunn et al. 2017, Glasby and Dickenson 2014). Cooperation and collaboration of different organisations is the main idea of integration in public health (Axelsson and Axelsson 2006). Smooth service delivery, accessibility and quality are all associated with inter-agency partnerships (Bunger et al. 2014), therefore interorganisational cooperation may bring integration of activities, increased efficiency, and reduced costs (Provan and Milward 2001). Nicaise et al. (2013) sustain that integrated services provide higher quality care because of the accountability as individual service providers and responsibility as a whole collaborative network. For individual service agencies to join a larger coalition or develop partnerships they look for resource availability and referrals, or authoritative pressure from policy makers and funders may also persuade an agency to become affiliated. (Bunger et al. 2014). That coalition can be considered a network when many autonomous organizations cooperate legally and provide an assortment of programs and services (Provan and Milward 2001). Beatá (2013) indicates step one in providing efficient assistance is acknowledging the need for human service organisations to build a network either naturally occurring or through regulations, thus promoting interorganisational networks as a common mode of service delivery in the public system (Provan and Milward 2001).

When care is provided by separate agencies in a fragmented service delivery system, the quality is fragmented as well, dependant on the individual services (Nicaise et al. 2013). Strandberg-Larsen and Krasnik (2009) propose that integrated care results in improving consumer health, increasing service satisfaction, higher quality care and lower costs. Kodner and Spreeuwenberg (2002) explain how integration of health systems and service delivery, is a means to integrated care. The International Journal of Integrated Care specifies a distinction between integration and integrated care. Integration is recognized as processes and structures that promote the delivery of services, and integrated

care is defined as the philosophy of improving quality-of-care, consumer experience, and cost-effectiveness of care services (Oelke et al. 2016, Kodner and Spreeuwenberg 2002). The terminology relative to integrated health care is confusing, at times undefined and at times interchangeable (Strandberg-Larsen and Krasnik 2009). Although ubiquitous in the literature, there is no consensus on a definition for integration, thus it can be considered a flexible term (MacAdam 2008). Based on a literature review of various definitions, Strandberg-Larsen (2011, p8) proposed a definition:

“Integrated healthcare delivery refers to a coherent and coordinated set of services that are planned, managed and delivered to individual service users and populations across a range of organizations and by a range of cooperating professionals and informal careers. The essence of integrated healthcare delivery is that individuals and populations alike receive - best practice based-services they are in need of, when and where they need them for optimization of health status, and that all services are delivered in a cost-efficient way, seen from a whole system perspective.”

Further discussion includes Lawrence and Lorsch (1967), who define integration as “the quality of the state of collaboration that exists among departments that are required to achieve unity of effort by the demands of the environment” (Axelsson and Axelsson 2006).

## Models of Implementation

Comparable to the lack of definition consensus, the literature indicates there is also no standard approach to the implementation of integrated care. In a review of models of implementing integrated care for older adults, MacAdam (2008) dissects integration and divides it into essential nested components: types, types referring to Leutz’ levels of integration described subsequently; levels, such as system, organizational and clinical, expanded on subsequently; and forms, horizontal, across settings, or vertical, within one organization. Kumpers (2005) distinguishes between different perspectives of integrated care: policy, logistic, patient, organisational, and economic. Strandberg-Larsen (2011) adds to Kumpers’ (2005) list the clinical practice and public health perspectives. Minkman (2016)

developed the comprehensive Development Model for Integrated Care (DMIC), which incorporates 89 elements into 9 clusters into a self-assessment web based tool. Alternatively, the Rainbow Model of Integrated Care (RMIC) interconnects the macro- (system integration), meso- (organisational and professional integration) and micro- (clinical, service and personal integration) levels (Valentijn et al. 2017, Nurjono et al. 2016). Harnett et al. (2019) propose a 10-step framework to implementing integrated care for older persons based on whole system transformative change and cultural dimensions. The SELFIE (Sustainable intEgrated chronic care modeLs for multi-morbidity: delivery, Flnancing, and performancE) framework for integrated care for multi-morbidity (Leijten et al. 2018) originates through an EU project of eight countries. Elements are grouped by the micro, meso, macro levels of a health system and further categorised into the key strategies structuring the aforementioned WHO framework (2016).

In sum, there exist a breadth of approaches to implementing integrated care that put forward a myriad of perspectives, levels, types, forms and dimensions. Strandberg-Larsen (2011), similarly to Valentijn et al. (2015), urge that it is fundamental for a researcher to make clear exactly which definition they will work with because each stakeholder has their own interests dictating which definition of integration to measure.

For the purpose of this study, I chose to approach integration from the public health perspective as defined by Strandberg-Larsen (2011):

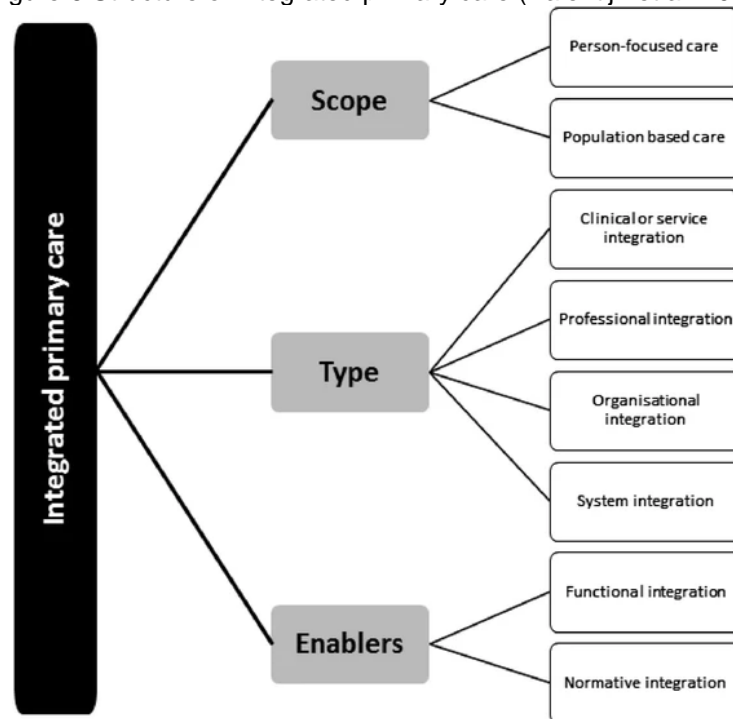
“Focus is on providing the population and/or high risk groups within the population with services needed for optimization of population health. This perspective will often go beyond the realm of healthcare, and coordination of services will therefore also be expanded to include social care services or similar.”

This public health perspective explicitly states the inclusion of social care within healthcare, a fundamental element of the biopsychosocial model and the integrated care concept.

To further frame this study through an integration lens, I selected the integrated primary care structure of a service model developed by Valentijn et al (2015).

Through a systematic review and Delphi study, Valentijn et al. (2015) developed the structure consisting of three main domains: scope, type, and enablers (Figure 6). Each domain is intended to delineate and interpret objectives and guiding principles in implementing an integrated care approach service model. This structure is organized and straightforward while encompassing many of the elements featured in the aforementioned models.

Figure 6 Structure of integrated primary care (Valentijn et al. 2015)



In conforming to the objective of this study, to assess the levels of integration of older adult and dementia service systems, the use of Valentijn et al.'s structure (2015) permitted a framing of the scope, type, and enablers of integration assessed. Pursuant to the structure, the scope of this study is population based, where the integration addresses the needs of a specific population, families living with dementia (ibid, p13). System type integration is the focus, where the aim of the integration is organizational processes and arrangements to enable the comprehensive delivery of care (ibid). The enablers, of an integrated service delivery model, examined in this study were the inter-organizational ties. These conform to the normative integration domain, defined as "mutually respected

cultural frame[s] of reference (i.e. shared mission, vision, values and behaviour) between organisations” (ibid, p10).

The service delivery structure by Valentijn et al. (2015) frames the components of integration this study focuses on. As outlined above, a variety of models and frameworks have been developed to implement integration through different perspectives and for different levels of health and care systems. The support for application of integration models to dementia is described next.

## Integration in Dementia Care

Within the realm of dementia care, integration is indispensable, as cognitive decline is conducive to functional and behavioural disturbances (Gould 2011). People with multiple needs such as persons with dementia that require multidisciplinary care covering physical, psychological, and social assistance, benefit from an integrated approach (Nicaise et al. 2013). Health and social care together, and combined with family carers, can provide support for the cumulative needs of people with dementia (Fox et al. 2013). Clients with conditions that have multiple needs have more difficulty being responsible for effectively coordinating their own care and treatment through a myriad of service agencies (Provan and Milward 1995).

For people with multiple needs such as those with dementia, it is particularly deleterious to navigate a commonly fragmented care and support system (Downs and Bowers 2014). As confirmation, a qualitative study on perspectives of access to formal dementia care, conducting expert interviews in eight European countries (Broda et al. 2017) found the themes cooperation, communication and networking emerged as necessities among sectors and disciplines. According to Gould (2011), the quality of care for many diseases that affect older adults is higher than that for dementia due to poor integration of organisations and the need for a systems based approach. For example, important community resources such as the Alzheimer’s association or caregiver support agencies are underused and fragmented within health systems (Reuben et al. 2013). An integrated system may increase the probability that all services are provided within the system and

minimizes duplication of services by multiple agencies (Provan and Milward 1995). For families with dementia, collaboration between care and support providers is vital to continuity of care (Minkman et al. 2009). Thus, the organisation of dementia specific systems of practice and exchange between associations is needed (Fox et al. 2013) to enable families and health professionals to manage their multiple needs (Bunn et al. 2017).

As outlined in a previous section, current approaches to dementia and to models of dementia care sustain the importance of the relations between an individual's biological, psychological, and social dimensions which encompass the interactions with the environment and a person's spirituality. This is represented in this study through the biopsychosocial model of health which is paralleled in service delivery by the integrated care concept. Concurrently, a global dementia policy movement is spurring policy makers to act, and a case is made in the literature, as discussed above, for an integrated health care system to provide a comprehensive model of care, specifically for people with complex needs such as those living with dementia. "System level integration, as measured changes in relationships between organizations, has been associated with improved access to services and improved outcomes" (Davis et al. 2012, p266). Consequently, models of system integration are valuable, as much as methods of evaluating system integration are essential. These will be discussed in the next section.

## Models for Assessing Integration

Through a systematic literature review, Strandberg-Larsen and Krasnik (2009) found twenty-four methods used to evaluate integrated care delivery. The European Centre for Social Welfare Policy and Research's study (2003) was discarded because it is structured to measure outcomes, thus more related to effectiveness of integration. The four remaining methods focused on service integration and inter-collaboration adaptable to the older adult and dementia service systems. Two of these were excluded after reading the studies because Ahgren and Axelsson (2005) examine clinical integration and Hebert and Veil (2004) measure the implementation of specific components into a system.

Of the remaining two pertinent studies, one was by Browne et al. who developed the Dimensions of Human Service Integration (2007) following an extensive review of frameworks and basing the methodology on Donabedian's Quality of Care model (1966). Donabedian (Figure 7) proposed the concepts of structure, process and outcomes to evaluate quality of care in the health sector (1966, 1997). Mirroring this model, Browne et al. (2007) presented structural inputs, functioning, and network outputs as dimensions for measuring whole network integration (Figure 8).

Figure 7 Quality of Care Model

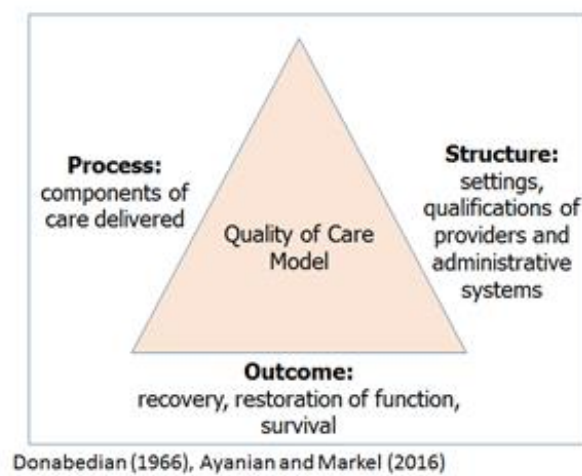
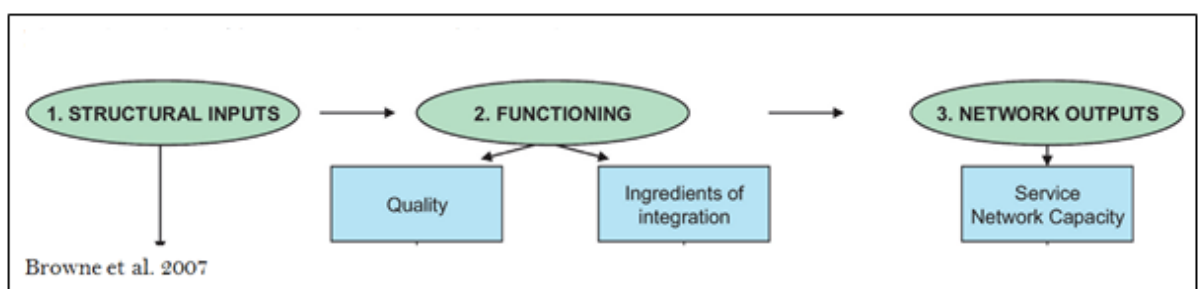


Figure 8 Dimensions of human service network integration



The second model used to assess integration and applicable to my study, was Leutz's Levels of Integration, which describes three levels of integration within

care delivery systems: linkage, coordination and full integration (Leutz 1999, 2005, Nicaise et al. 2013).

Although this model does not provide a methodology to measure the three levels, Leutz's is the framework I selected to use for this study because the definition Leutz applies to his model resonates with models of dementia care and with the descriptions of integrated care needed for families with dementia.

According to Leutz's model, integration is a) the connection of health care services to other human services as a means of improving efficiency and client satisfaction, and b) the formation of managed care organizations that provide health and social support or a closer coordination of individual care (1999, 2005). In the literature of integrated care and integration in dementia care, the divide between the health and social service sectors is indicated as one of the causes of service fragmentation, resulting in low quality care. The underlying theme of the biopsychosocial model of health is the interconnectedness of the health and social dimensions. Additionally, Leutz' definition of integration includes the element of coordination of care, which the lack of is deemed to augment fragmentation of care. How I applied the model in assessing levels of integration is outlined in chapters 3, 7 and 8.

Leutz believes that by interconnecting the various sectors of a health system, the result will be improved outcomes for users (1999, Raco 2019). In his seminal article, *The Five Laws of Integration* (1999), he explains how the three levels of integration enable sectors and disciplines to work together. Combined with Nies' interpretation (Nies and Berman 2004) and Shaw et al.'s adaptation (2011), the levels can be described as: the linkage level addresses mild to moderate needs through the existing services which commit to good communication to promote referrals and continuity of care; the coordination level is moderately more integrated where acute episodic needs and/or multi-sectoral and multi-disciplinary needs are coordinated across settings in a more structured manner in sharing information and managing transitions; the full integration level manages and controls all of the care for moderate to severe needs and/or complex comorbidities by creating new multidisciplinary pooled service programs to provide comprehensive care.



The underlying theme in Leutz's model is organized and coordinated interaction between parts. Engel's biopsychosocial model of health (1977), described in an earlier section, claims a fundamental aspect of dementia care is the connection between and collaboration of biomedical health care with other human services. Thus, Leutz's framework is highly relevant and more targeted than Browne et al.'s framework, which focuses on outputs and outcomes of the system. In addition, Nicaise et al. (2013) recommend that in the delivery of social and health care, fragmentation should be addressed at the system level for example by using Leutz's levels of care integration.

Where Valentijn et al.'s integration structure frames the scope of integration studied, Leutz's (1999) levels of integration provides a model for assessing the integration.

## Integration in Developing Countries

There is a shortage of examples of implementation of integrated care for older adults especially from low- and middle-income countries (de Carvalho et al. 2017). Integrating care programs for older adults and the disabled would increase care delivery efficiency in developing countries (Prince et al. 2009). The benefits of integrating care are presented robustly in the integrated care and the dementia care literature discussed in the previous sections. Yet, implementation of integrated care models and frameworks in low resource contexts has not been evaluated (de Carvalho et al. 2017). The WHO (2010a) states that to improve health programs' effectiveness in developing countries, it is necessary to understand the systems better. Understanding how health systems are structured leads to design improvement interventions, especially in developing countries where health systems are less developed (Blanchet and James 2012). More specifically, people with dementia are estimated to be found predominantly in developing countries, yet research has primarily focused on the developed regions (Prince et al. 2012, 2013, Johansson et al. 2019, Brito-Aguilar 2019). Reiterating

what was stated in the introduction, there is a lack of research in dementia in developing countries, which includes data on formal and informal care systems (Prince 1997, Prince et al. 2004, 2013, Russ et al. 2012, Kalaria et al. 2008, WHO 2000).

The role of the health care system must consider the patient and the living context, society and the social norms regarding the patient's condition (Engel 1977).

Preventing complications and meeting these diversified needs of families with dementia require a network of health and care services (Gould 2011).

The literature indicates, and I argue, that an integrated care system is the enactment of the biopsychosocial model of care on a macro system level. Both concepts are founded on the idea that the interactions between health and social disciplines and sectors lead to providing quality health care in the means of addressing complex needs, providing coordinated care, and continuity of care.

## Conclusion

In this chapter, I have laid out the foundations of this study through a review of the literature. I have discussed approaches to framing dementia and models of care, and how the biopsychosocial model can be considered an anchor encompassing the other theories. This discussion highlighted the importance and need for framing dementia through the interactions of an individual's various domains, and why dementia care must be multidisciplinary recognizing potential complex needs. I outlined international dementia care policy demonstrating that it is linked to the concepts of integration and integrated care because policy provides the foundations and guidelines to deliver appropriate care. Additionally I illustrated why system integration is fundamental in providing families with dementia coordinated services and continuity of care, and improving outcomes access to care. Finally, I highlighted the gap in research on assessing system integration especially of dementia service systems in developing countries.

In the following chapter, I introduce, through a critical realism perspective, international comparison research and social network analysis, the methodologies guiding this study. I also outline the research design process in all of its steps.

# Chapter 3: Methodology

## Introduction

In this chapter, I discuss my epistemological position associated with the methodological approaches, and explain how their uses allowed me to consolidate participants' subjective relationships in order to gain an understanding of the greater objective social systems in existence. I will then discuss the research design, and reiterate the choice of the research settings. Next, I will discuss ethical themes and the methods used for data-collection. Finally, I will outline how I constructed datasets for analysis, how I carried out data-analysis and how I managed the data.

Research methodology and research methods are related terms with distinct definitions. Methods are tools, techniques and instruments used by researchers in order to conduct research or collect data. To answer research questions systematically, research methodology is necessary (Kothari 2004). The research methods are part of the larger methodology, which explains how and why a study will be done and the reasoning behind the selection of particular methods and procedures.

Critical realism is the perspective through which this study has been framed. Considered a philosophical approach to research, critical realism considers that a natural order in social events can be discovered not only by observation but also through process of interpretation, which is open to revision as understanding grows (Buch-Hansen 2014). Through this lens, ontology remains a product of its social context but also takes into account an objective reality (Houston 2001).

Critical realism is concerned with the nature of causation, agency, structure, and relations (Archer et al. 2016). As critical realism explores the relationships between social structures and agency (Price and Martin 2018), this study investigated social interactions and social structures through the methodologies

described below. Individual relationships become interactions between organizations, in my research. These interactions are both realist and social structures. They in turn create the interorganisational networks meant to provide care to the individuals. By combining interpretation, of the interactions by those participating in the interaction; and explanation, of the existence of the interactions; we can view the relationships between individuals as they interpret networks that can be analysed objectively as entities or social structures.

Through the critical realist lens, I selected the methodology, developed the methods, and completed the fieldwork guided by my research questions reiterated here:

- How are older adult services structured in Central American countries? What are the relevant regional and national policies, what services are offered; what types of services are dementia specific?
- How integrated are the networks? What integration levels do the node & tie attributes suggest; what integration levels do the network measures suggest?
- How do the dementia specific networks compare to the whole networks? How do the positions of families in the networks affect care/support
- What is the impact and what are the implications of my findings?

I applied two methodologies, which guided my decisions on designing and executing the research, and on how to analyse the data collected. I will discuss how the international comparative approach and social network analysis shaped my study in the sections following a first part dedicated to my epistemological position.

## Critical Realism

In choosing a methodological approach to a study, one must begin with acknowledging one's paradigm, a worldview, or set of beliefs, that ontologically and epistemologically guide the researcher (Guba and Lincoln 1994). Through the

recognition of my own values and beliefs of my place in the world, I selected to take the epistemological position of critical realism. As defined by Scott (2007, p14),

“critical realism is realist and critical for two reasons: objects in the world, and in particular social objects, exist whether the observer or researcher is able to know them or not; and secondly, knowledge of these objects is always fallible because any attempts at describing them need to take account of the transitive nature of knowledge.”

Critical realism acknowledges the relationship between structure and agency, as fluid, the key idea being “social structure exists only in and through the activity of human agents, even though it is not reducible to such activity” (Lawson 2007, p38). In as such, social structures’ existence is dependent on the conception and activity of agents. Social activity is, according to Lawson (ibid), held within the social relations domain, parallel to the social domain of the biopsychosocial model and integration concept supporting this study as described in chapter 3, and of social network analysis, the main methodology framing the research design.

Social Network Analysis (SNA) is a methodology used to explore relationships between actors, to identify the patterns of the relations between them, and to analyse the effects that the structure of the patterns has on them (Scott 2011). The examination of the relations between people directly refers to the critical realist perspective, treating relations as objects of perception and measurable reality. SNA will be described in depth subsequently, but the clear connection between SNA and a critical realist position is made here.

The association between critical realism and SNA, compiled from literature of leading network scholars by Buch-Hansen (2013), is outlined in six theoretical, mutual points:

1. Depth realism: social relations exist independently of social construction, as they are observable and produce structures that cannot be seen - networks.
2. Agency and structure: Structural positions influence both actors and social structures.

3. Emergence: social ties are new entities created by the connections between two actors but with different properties than those creating the tie.
4. Open systems: data collected for network studies are part of the social world, therefore in open systems, and although boundaries are created for the sake of delimiting research criteria, actors are related thus not considered isolated units.
5. Knowledge: is a process of continuing contributions where the known is the building block of the unknown and is undetermined and transitional, as networks are dynamic.
6. Social science: the discovery of underlying social substructures and mechanisms of social events is an essential root of social scientific knowledge production.

Although SNA does not lend itself to establishing causation, also outside of the scope of this study, SNA does meet the purpose of rendering visible invisible social structures and the social relational mechanisms that form them. Therefore, SNA, in this study, sustains the critical realistic view that there is

“a world which exists independently of human perception, that human knowledge of that reality is often limited and contingent, and that it is possible to judge between competing truth claims while recognizing that such judgements are open to revision” (Walker 2017, p116).

A detailed description of SNA will link to Walker’s quote in a subsequent section. First, I will discuss the application of the international comparison research approach that framed the first and more general part of the study relative to the selection countries.

## International Comparative Research

Purposes for undertaking cross-national research are diverse and include establishing common goals or problems and examining how different countries achieve or tackle them and if any best practices or policies can be transferred to other countries (Cacace et al. 2013). My goal was to extend knowledge about

dementia service systems by developing new insights, testing theory against practice, understanding how processes operate, increasing the awareness of cultural diversity, and learning from an exchange of information and experiences (Hantrais 2009). The comparison between Central American countries was intended to acknowledge the region within ageing and dementia research as it is considered a terra incognita, by providing an explorative overview.

International comparative research requires the comparison of two or more countries, societies or cultures. Using the same research tools to "compare systematically manifestations of phenomena in more than one temporal or spatial sociocultural setting" in studies of societies, countries, cultures, systems, institutions, and social structures is labelled comparative research (Hantrais 2009, p.2). This study completed a comparison between five of the seven Central American countries. Concept definition is key in comparative research, on which I will expand later, thus the need to briefly discuss the term used to name what is being compared. The term cross-national creates some perplexity as to how context is accounted for, where the prefix inter, inter-national, implies the inclusion of context and its relationship with the phenomena being studied. The framing of a nation also constitutes debate. The political, cultural, territorial and ethnical aspects of populations need to be identified as context or separate units of analysis. I will use Hantrais' (2009, p. 4) definitions of nation: "a geopolitical and sociocultural entity", and of cross-national comparative research: "comparisons across legally delimited and administratively implemented national boundaries, recognizing that different countries, societies or cultures are contained within increasingly fluid borders".

Dealing specifically in the field of health care systems and policies, Cacace et al. (2013) provide criteria for country comparison research. Their study sums up the views of members of the European Health Policy Group (EHPG), who are consistently undertaking or using cross-country comparative studies, regarding basic criteria. Five essential criteria emerged to assess the quality of cross-country comparison studies: 1) adequate use of theory; 2) explicit country selection; 3) rigour of the comparative research design; 4) dealing with complexity

of country level comparison; 5) contribution to knowledge. The aforementioned theoretical framework meets the first criteria and the next section, Units of Analysis, meets the second. Rigour in research design is described in the subsequent sections and the Research Design section. I strove to meet criteria number four by being consistently and accurately aware of the context, in concept construction (described subsequently) and in describing the countries' circumstances. The fifth criteria, contribution to knowledge, is described in the final discussion chapter.

### Units of Analysis

In this section I explain the method used to meet the criteria for explicit country selection, ascertained essential by the aforementioned study (Cacace et al. 2013). Units of analysis in international comparative research may be whole regions, countries, societies, cultures, or subdivisions and or subgroups of individuals with some shared structure or aspects. At least three of the seven countries of Central America: Belize, Guatemala, El Salvador, Honduras, Nicaragua, Costa Rica and Panama were to be my primary units of analysis. The criteria for inclusion in my study were: 1) the countries are of the same region; 2) the countries are all members of the SISCA, the organization that unites them in social integration. The selection of countries provides a contextual framework and their membership to an organization is a shared reference point (Hantrais 2009). This reference point indicates shared goals, thus a common characteristic of their national identity. Nations provide clearly defined boundaries yet at the same time idiosyncratic internal systems and cultures. Idiosyncrasy and dynamism are well noted in networks for example; because they are based on relational ties that are constantly evolving, thus limit the data to a specific temporal space. Sociocultural systems develop and are implemented in different ways, which can be compared to find parallels, contrasts, and isolates (Hantrais 2009).

I initially proposed to remain flexible to study between three to seven countries, planning to decide in the field with a realistic understanding of time and feasibility



conditions. My plan of action if data collection proved prolonged and highly intricate was to focus on three countries: Guatemala, El Salvador, and Panama. This decision was based on the factors that differentiate them the most within the region, geographically, demographically and socio-politically, with the aim to paint a contextually inclusive portrait of the region, should it not be possible to include all seven countries.

Guatemala is the largest country of the region (~16 million pop., Table 6) with the largest indigenous population. It shares its northern border to a non Central American country, Mexico, and was the first to implement a national law protecting older adults. El Salvador has a mid-size population (~6 million pop.), is one of the most socio-politically unstable countries of the region and most influenced by the United States (Booth 2010). Panama is the smallest country (after Belize, ~4 million pop.), also shares a border with a non Central American country, Columbia, and was the last to implement a national law protecting older adults.

Over the course of the fieldwork I was able to collect data from five of the seven Central American countries; El Salvador, Guatemala, Honduras, Panama and Costa Rica. I did not collect data from Belize or Nicaragua. Before beginning fieldwork, I discovered that the international older adult NGO HelpAge had an office in Belize. I contacted them seeking possible support from colleagues in the region in the means of contacts and information on the contexts, with in turn a system perspective of Belize, which they might find useful. After some bureaucratic communication regarding my study, HelpAge advised me that to do fieldwork in Belize I was to apply for ethical approval from each organization before arrival. Though I explained that I had already obtained ethical approval from my university, and the sampling methods (described subsequently) could not support what they requested, it was intended that I could not proceed. For this reason I decided to exclude Belize from the study. Nicaragua was excluded because of civil/political unrest that began when I was in Honduras, and that developed into a revolution with the closing of its borders. I was recommended to fly over Nicaragua as the unrest intensified, which I did.

## Concept and Measurement Equivalence

Comparative research that crosses national, societal, cultural and linguistic boundaries must use clearly defined concepts and relationships between concepts and contexts. Concepts are integrated within contexts thus understood and interpreted differently. This is the principle of the context-boundedness of concepts (Hantrais 2009). A concept is the aggregate of ideas and meaning related to a term, and is the basic unit of operation of social scientists (ibid). Dementia and dementia care are the chief concepts of my study. My first goal was to explore how these terms were used and understood in Central American cultures. From observations and interactions with people from Latin America prior to starting my thesis, I had previously noted that the word dementia did not resound familiar, though it does exist in the Spanish language, instead the word Alzheimer triggered recognition. Evaluating the influence of external factors on concept evolution is how comparative analysis can inform policymaking. "Culture serves as a framework for organizing, analysing, and interpreting actions, motives, attitudes and values" (Hantrais 2009, p. 54). Case in point, if the concept of dementia or dementia care is not present in the culture, it will not be taken into account in policies at any level. The social construction of concepts in cross cultural and linguistic research is also fundamental to describing a system. Delineating the concept allowed me to develop inclusion criteria for organizations of the service system.

Defining and contextualizing concepts has a potential for slippery slope, too broad or flexible. Sartori (1994) referred to concept stretching as definitional sloppiness, when a concept's definition is vague, inconsistent, decreasing its validity. Sartori developed the Guidelines for Concept Analysis (1984) to assist researchers in making terms universally understood, unambiguous and consistent. It is the researchers' responsibility that terms be adequate, identifying boundaries and referents, and parsimonious in excluding inferences or proximal aspects. That concepts under study have the same meaning in different contexts in international comparative analysis is key and is labelled concept equivalence (Hantrais 2009). I have previously defined the concepts of dementia and dementia care as they are constructed in LMIC countries, but as I planned, I began fieldwork in each country

with a layperson's description of older persons with forgetfulness or needing assistance and let myself be led by the people and organizations I interacted with in building the concept. I wanted to let the context not only construct the concepts, but also the terminology I would use.

I found that people working directly with older adults, and especially with people living with dementia, were aware of the term dementia and used it interchangeably with Alzheimer's, but most often only used the latter. Healthcare workers, families and laypeople in general, were not familiar with the term dementia, although a minority did recognize it during conversations where Alzheimer was mentioned. Throughout the duration of my fieldwork, even when socializing, I allowed the context, the culture, and the people to use their terminology.

Measurement instruments also require attention to equivalence. I used questionnaires to guide semi-structured interviews and to enable cross-country comparison as per Rokstad et al. (2016). The questionnaires consisted of 3 open-ended questions and 3 items with numerical Likert scales, recommended as universally understood response scales (Hantrais 2009). Translation must also account for context in cross-national comparisons, survey and interview questions cannot simply be translated without considering their purpose and referential meaning. The questions should provoke the same reaction and incentivize the respondents in the same way in different cultures (Hantrais 2009). Therefore, context and conceptual equivalence are elements that must also be included when translating, to avoid possible ethnocentrism through translating words rather than allowing context to frame social phenomena. According to Hantrais (2009), a way to allow context to shape concept construction is a researchers' local knowledge and familiarity with the culture and the concept itself. My being from a Latin country, which shares cultural values, traditions and religion with Central American countries, provided me with familiarity. I speak the chief language of the region, Spanish, and had previously visited the region. I was able therefore, to compile the interview guides directly in Spanish.

Additionally, my job experience working directly with organizations and people with dementia and their families in their homes and in institutional settings, included

many families from the Central American region who only spoke Spanish. This practice provided me the basic tools to carry out my research, which will be outlined in the research design section.

## Social Network Analysis

Social network analysis (SNA) is the methodology further delineating the scope of my study. SNA is a framework for collecting and analysing data (Tichy et al. 1979). Organizational processes can be explored at, and by linking, different levels of analysis. The social network approach "views organizations in society as a system of objects (e.g. people, groups, organizations) joined by a variety of relationships. (...) it is concerned with the structure and patterning of these relationships and seeks to identify both their causes and consequences" (Tichy et al. 1979, p. 507, Howe et al. 2004, Fulk 2001). Furthermore, these relations produce a reality independent of the perception of the people involved as per Walker's aforementioned description (2017). That reality is the networks, or the consolidation of interactions between organizations, which are unperceived through the individual interactions.

Social Network Analysis (SNA) is a method and a paradigm (Blanchet and James 2012). In SNA the nodes are the actors, the ties are the relations between the actors, and the structures made by those ties are analysed (Scott and Carrington 2011). A set of socially relevant nodes that are connected is a social network, people or organizations are the nodes, and the study of the patterns of relations between them is SNA (Marin and Wellman 2011). The notion of social interaction can be visualized empirically through the image of the social network (Miller 1980). Members of society at both individual and organizational levels are linked through networks (Beatá 2013). Networks are made up of a set of people or organizations and a set of connections between them measured through observed or reported communication (Dunn and Westbrook 2011). A network approach looks at the strengths and the nature of connections, and sees individuals to be participants in

groups to varying degrees, group structures to vary, and sets of people not necessarily forming groups as forming social relations (Provan and Milward 1995).

Networks can be analysed through egocentric network studies, which are focused around one actor, or via whole network studies, which measure the structure of a delineated social group that includes an egocentric network for each actor within the group (Marsden 2011). The egocentric network is the simplest level of analysis of social networks because it studies the main actor, the ego, the other actors the ego has direct relations with, referred to in SNA as alters, and the direct relations among and between those alters (Knoke and Yang 2011). The study of whole networks measures the structure of various types of relationships within a socially bounded group (Provan and Milward 1995).

SNA allows an evaluation of the organisational relationships within a care system (Nicaise et al. 2013) and can be used to describe and understand communication patterns (Browne 2007), as Moreno showed in 1934 by applying sociograms and social network theories in public health. When looking at the collaboration of organisations within a system, network analysis is key (Dunn and Westbrook 2011). Social network analysis can be useful to foster collaboration within the system (Beatá 2013). The flow of information within a system is analysed through SNA and understanding the processes of sharing information can influence a health system's structure, and vice versa, the structure can be influenced by how information flows through it (Blanchet and James 2013). "SNA can provide a useful framework and key policy indicators for evaluating possible gaps across different types of inter-services integration" (Nicaise et al. 2013, p338). A limitation of SNA is that within a system network, participating agencies are always inserted in more than one network in various types of ties (Nicaise 2013). Another is that networks change over time (Blanchet and James 2013) and the definition of the actors within a network, thus inclusion criteria that delineate the types of relationships do also (Nicaise 2013).

Whole network studies are at the macro level of analysis of any type of social informal or formal group ranging from physician practices; regulars at a beach;

employees of a fast food chain; professors of universities; schools, administration associations, and unions of a school district; or social/health delivery systems (Marsden 2011, Knoke and Yang 2011). Actors of a whole network study can be people such as members of a family, groups such as the girl scouts, local councils, or organizations, for example the organizations that provide services to persons with disabilities.

Specifying the boundaries of a network in SNA can be problematic with informal groups, such as the examples of regulars at a beach or organizations of the disabled service delivery system, nonetheless using inclusion criteria results in a roster of the study population (Marsden 2011). For instance, the boundaries of the whole networks just mentioned could be specified as: regulars of a specific beach, or the disabled service delivery system of a specific city. These boundaries inform the inclusion or exclusion of actors and their interactions. The boundaries determining the networks for this study are the older adult and dementia service systems of five Central American countries, and will be further outlined in the network boundary section.

Networks have been established as the most important organizational structures as of the beginning of the 21st century, claims Fulk (2001). SNA allows an evaluation of the organisational relationships within a care system (Nicaise et al. 2013), and can be used to describe and understand communication patterns (Browne 2007). From a literature review by Schulz-Jones and Macpherson (2006) a total of 21 studies resulted as published between 1999 and 2005 using SNA in private and public organizational settings, and they concluded that to examine the structure and behaviour of organizational networks SNA is a valuable methodology. Blanchet and James found that in 2012 SNA had not yet been applied to health systems in developing countries. This was further confirmed in a systematic scoping review by Chambers et al. (2012) on social network analysis in healthcare settings, where one in 52 studies was from a developing country. In recent years, the use of SNA in public health research has increased (Shelton et al. 2019), yet in developing countries it remains sparse.

The aim of this study was to explore the dementia service systems of five Central American countries through social network analysis. Looking at the network as a whole can be considered a perspective where elements of a whole social structure, such as a health service system, are explored and can infer information about the structure's mechanisms (Hanneman and Riddle 2011). This study employed social network analysis following the methodology developed by Blanchet and James (2012) because their seminal article was based on the same context, a health system study in a developing country. In addition, Blanchet and James (ibid) provided a straightforward and clear approach that was not found in other studies.

This approach (ibid) consists of three stages: (1) defining the network boundary or the list of actors and the members of the network; (2) collecting and analysing data on the relationships between actors; and thus (3) analysing the structure and dynamics of the social networks. The completion of the first two stages is explained in this chapter, the third stage of analysis is outlined in the findings chapters 5-7.

### Network Boundary

Similar to deciphering the units of analysis when using the international comparative approach, in SNA deciding who or what organizations to include in a network is termed specifying the network boundary. Three different approaches identified by Laumann et al. (1983 in Marin and Wellman 2011) can be used for network boundary specification: position, event and relation (Marsden 2011, Tichy et al. 1979, Blanchet and James 2012). A position approach includes members of an organization or hold a specific position, such as researchers holding post-doc positions in a university, and all others would be excluded from the network. An event approach would include only participants of a specific event in the network, such as attendees at a conference. A relation based approach, which I used, starts with a small set of nodes (organizations) with shared criteria then expands through the relations of those initial nodes (Marin and Wellman 2011). Beginning with central organizations is recommended when researching service delivery systems (Tichy et al. 1979). The boundaries for the whole networks of this study

were organizations providing services to older adults and/or families with dementia, and in each Central American country a central organization of dementia service systems, an Alzheimer's Association, was present.

I followed three processes outlined by Knoke and Yang (2008) for generating a relation based network:

- the reputational method: asking the most knowledgeable informant to name a set of actors;
- snowball sampling: actors are asked to nominate other actors with whom they have a relation, these other actors are asked to nominate yet other actors with whom they have a relation and so on and so forth until few or no new names are elicited;
- expanding selection: respondent is free to name the actors they relate to.

Further, it was important to decide what would constitute an organisation within the networks. In this study, a family is considered an organization, as per Waite's (2000) description of families as the founding social institutions of all societies and therefore social organizations. As Waite outlines, families are "responsible for production, distribution and consumption of commodities as well as reproduction, and socialization" (2000, p464), including care and support for each other. Evaluating social organizations constitutes assessing outputs relative to other social institutions and society in general. Families, according to Waite (2000), can be assessed through the same methods. Families are vital nodes to include in the service networks, because they provide primary care and support to family members with dementia; because they provide care and support to each other through support groups; and because they are the intended recipients of the services from the other network members.

My first interview in each country, except for Panama, was with the Alzheimer's associations. I asked them to name a set of organizations they either collaborated with or deemed service providers. In the successive interviews, I supported snowball sampling to enlist additional organizations which provided services for people with dementia and to confirm network affiliation. I wanted to allow the network to be expanded freely. A family with dementia embedded in each network



was identified via the reputational method from the Alzheimer's associations or in the cases of El Salvador and Honduras, from families. The families provided a perspective of the dementia service networks by confirming or adding organizations from which they received services or to which they were affiliated.

## Types of Ties

After having determined the boundaries of the network, the types of ties between the organizations included had to be established. Understanding what type a tie is, describes what type of connection exists between two nodes, or two organizations. The selection of which types of ties to measure is highly dependent on the data retrieved, thus was decided after data collection. Relating back to context boundedness, ties is a term that needs defining, as it is embedded in context (Hawe et al. 2004). Ties can be classified in various ways; similarities, social relations, interactions and flows are four categories of ties indicated by Borgatti et al. (2009). Social relations, interactions and flows were selected to be the three types of ties to focus the items of the interview guide. Classifying ties by similarities was excluded as more suitable to egonets where similarity is based on traits and demography.

Affection or kinship are commonly identified as social relations, while an action between two nodes such as speaking or helping is an interaction, and flows are exchanges of information, resources or influence. "A well-integrated network is defined as a network in which all organizations are connected and the resource exchange among all network actors is guaranteed" (Raeymaeckers 2013, p. 416). Rosenheck et al. (1998), Morrissey et al. (1994), and Blanchet and James (2013) indicate information and/or funds as types of resources to be exchanged in service ties between organizations, while others also indicate referrals (Wang et al 2016, Davis et al. 2012, Nicaise et al. 2013). These examples led me to assess which resources were exchanged between ties by adding the item "What do you and X

(nominated organization) exchange?” onto the interview guide. This resulted in findings on the types of ties present in the systems, and what was exchanged through those ties. These elements, types of ties and exchange, were the cultural facilitators, or nominative enablers of integration, as per Valentijn et al.’s (2015) integration structure, described in the previous chapter.

## Network Analysis

The data collected on networks is calculated to measure various properties of the whole network, and of the positions of the nodes forming the network. Specialized software, UCINET and Pajek were used to perform the calculations. The key is that the analysis of the pattern of connections between nodes provides an explanation about how the network functions. The five essential properties of the whole network to measure in an analysis of a health system, according to Blanchet and James (2012) and sustained by other studies are:

- 1) betweenness: how much an organization connects other organizations to each other
- 2) centrality: if there is an organization playing the central role of the network
- 3) density: the proportion of ties connected to one another
- 4) distance: how many steps from one organization to another organization
- 5) reachability: the maximum number of steps needed from one organization to any other organization within the network

(Nicaise et al. 2012, Provan and Milward 1995; Morrissey et al. 1985, Davis et al. 2012, Dunn and Westbrook 2011).

Taking these studies above as examples, this study measured four network properties: density, centralization; and two other properties that did not appear in health service studies but did in management studies: E-I index, a method of measuring the number of external to internal ties within similar groups, in SNA also termed homophily and heterophily, (Galelli 2016), and quadratic assignment

procedure (QAP), a measure of correlation between networks, found in teamwork and friendship research (Sonnenburg-Klein et al. 2017, McKay et al. 2017). These properties are described in detail in the network findings chapter 7. Following the literature, density and centralization were measured as fundamental indices of proportion of connectivity, and centralization also as an indicator of coordination. The E-I index was used to measure how many ties existed to external organizations, compared to the number of ties to internal or same types of organizations. Lastly, to explore the correlation between networks, QAP correlation was used. Comparisons between networks were made intra and internationally.

## Integration

The goals of the above analyses were to describe how the dementia service systems were structured, exploring similarities and differences, and to assess the levels of integration of the systems by relating network property measures to Leutz's levels of integration (Leutz 1999). The premise of this study, based on the literature outlined in chapter 2, was that an integrated system is needed to provide the integrated care that families with dementia need. Although Leutz's model does not provide a methodology to measure the levels, Nicaise et al. (2013) used the five key network properties outlined above by Blanchet and James (2012), and types of ties to understand levels of integration. Morrissey et al. (1994), Raeymaeckers (2013), Wang et al. (2016), and Davis et al. (2012) compatibly attest to measuring the properties density and centrality, providing further endorsement of the validity of these properties in assessing integration.

Based on the aforementioned studies, the indicators of integration were: the types of ties within a network, the strength of those ties, the proportion of reciprocity of the ties, and the exchange between those ties. As explained in the research design section, these indicators framed the interview guides, and the finding from the data expanded the indicators of integration. Each indicator represents a network, for example, all of the ties of one type constitute a network, or all of the

ties that exchange one specific thing constitute a network. This will be described in detail in chapter 6. The properties of each network were measured and the findings were applied in understanding the levels of integration, based on Leutz's model, of those health and care service systems. Measuring essential properties of the indicators via social network analysis, and combining those measures, allowed for indicative assessment of the integration level of each country's older adult and dementia service system.

## Reflection

Using social network analysis to assess integration was a complex task, not only because it was a new methodology for me, but also because various models for measuring and assessing system level integration exist. The selection and assemblage of indicators and measurements could not be made arbitrarily, thus the literature, the data, and the objectives guided the development of the methods framed by the methodologies. Nevertheless, where no standard exists, doubts remain. Perhaps other network properties, or other indicators, may provide other perspectives of the levels of integration. Through painstaking analysis of the data and review of the literature, I feel that the indicators used for arriving at the conclusive proposed integration levels, are robust. It is my attempt at forging a method to explore the structures of older adult and dementia health and social service systems.

## Research Design

The aim of my study was to provide an overview of older adult and dementia services of a habitually ignored region. The research design was exploratory, cross-sectional, using mixed methods. Five Central American countries were included in the study, in north-south order: Guatemala, El Salvador, Honduras, Costa Rica, and Panama. From February 1, 2018 until October 14, 2018 with a break in August, fieldwork was completed. Sixty-eight (68) semi-structured interviews were completed (Table 3), eleven of which were with families with

dementia, and the remaining with representatives of organizations providing services to older adults and/or families with dementia, such as care homes, hospitals, universities, private organizations, non-profits, and government agencies. The number of organizations nominated as having ties with the interviewed organizations are also shown by country in Table 3.

Snowball and reputational sampling methods were used, and together with the details of the participants of the study are described in detail in chapter 6.

Table 2 Number of organizations by country

	<b>GUATEMALA</b>	<b>EL SALVADOR</b>	<b>HONDURAS</b>	<b>COSTA RICA</b>	<b>PANAMA</b>	<b>TOTAL: 5 Countries</b>
<b>n. of interviews</b>	17	16	14	10	11	68
<b>n. of orgs nominated</b>	37	26	17	23	10	113

Surveys and interviews are the most common form of data collection in SNA (Schulz-Jones and Macpherson 2006, Hawe et al. 2004, Knoke and Yang 2008) and were the method of data collection for numerous studies using SNA in health systems (Blanchet and James 2013, Davis et al. 2012, Nicaise et al. 2012, Provan and Milward 1995, Morrissey et al. 1994, Morrissey et al. 1994, Raeymaeckers 2013, Wang et al. 2016, Rosenheck et al. 2000). Semi structured interviews was the chosen method of data collection. Although “time consuming and labour intensive”, semi structured interviews permitted the use of open and closed ended questions, and enabled dialogue delving in the hows and whys (Adams 2015, p493). Through semi structured interviews, service providers in each country’s older adult and dementia service network reported their perspectives on their relations with other providers. The items of the interview guides, outlined below, were developed based on the aforementioned integration indicators, and SNA survey and questionnaire examples found in the SNA Resources website (Borgatti 2020).

Information sheets and interview guides were prepared in both English and Spanish (English versions in appendices A-D). The information sheets provided

an introduction of me the researcher, and included: a brief summary of the project; a section specifying what was being requested of the participant; a section detailing how the obtained information would be used; an anonymity and confidentiality clause; and contact information of the researcher, my first supervisor, and the University of Stirling. This sheet was sent to each organization and family when requesting an interview, and again given in hand to each organization representative and family before beginning the interview.

Interview guides were made up of four parts (appendices C,D): Part I demographics; Part II included six open and closed ended items shown in Figure 9 that were repeated for each tie an organization claimed to have.

Figure 9 Part II of interview guide

Part II Interview guide

1. Which organizations are (were) you in contact with? *[Make a list]*
2. Which type(s) of tie do (did) you have with each organization?

a. social relation

i. How are you related?

--

b. interaction - speaking, helping

i. How does (did) the organization help you or what do (did) you speak about?

--

c. Flow - exchange of info, resources, influence

i. What does (did) the organization exchange with you?

--

3. How frequently do (did) you interact with this organization?

0 times per week	1-3 times per week	4-6 times per week	7-10 times per week
---------------------	-----------------------	-----------------------	------------------------

4. How important is (was) your tie with this organization?

0	1	2	3	4	5	6	7	8	9	10
Not at all										Very

5. How strong is (was) your tie with this organization? (can rely on)

0	1	2	3	4	5	6	7	8	9	10
Not at all										Very

6. How influential is (was) your tie with this organization? (impacts/affects)

0	1	2	3	4	5	6	7	8	9	10
Not at all										Very

Part III was identical to part II but referred to ties between organizations that were nominated by the interviewee; part IV two open ended items on existing dementia policies and care arrangements.

During the first interviews in Guatemala, I recognized that one item in part II, and all of part III were unnecessary. The item in part II required the interviewee to recall, with as much precision as possible, the frequency of interaction between themselves and any other organization they had nominated as having ties. I quickly discovered that for representatives of organizations, and families, this item cost time and effort. Although it was certainly, an indicator of interaction, without a tangible measurement of frequency, an approximate answer was neither reliable nor beneficial to the interview process. Therefore, I decided to skip the item moving forward. The same applied to part III of the guide, the same items of part II yet repeated to request hearsay from the interviewee. Part III was thought to ask a representative of an organization, or a family member, to report on the interactions between other organizations. This process extended the interview time dramatically, as interviewees ventured having accurate knowledge of other organizations' communication. After the first three attempts, I again realized that it would be detrimental to the interview process to include part III, time wise it was visibly tedious for the interviewees, and the approximation of the responses would detract validity from the study. I opted to exclude part III from further interviews.

One hour was allotted for interviews with one member of each organization of the service networks of a country, and two hours were proposed to spend with each family over coffee chatting about their experiences interacting with services and completing the questionnaires. Part IV, the open-ended questions on policies and care arrangements were intended as a close to the interviews, offering a context mapping of each territory. Flexibility was a vital point for this study, decisions regarding time spent completing interviews and generally in each country, were largely directed by in field circumstances such as the number of organizations in a network, the time needed to set up appointments with organizations and families and their availability to participate, and not in the least, how much time were interviewees willing to offer me in telling their stories.

## Ethical Approval

Ethical approval was obtained from the University of Stirling's ethical committee before commencing fieldwork (appendix F). This approval included the themes of anonymity and confidentiality, which were guaranteed for individuals and organizations as per Robins (2015, p.151) by "de-identification". Participants, including organizations, were coded with alphanumeric identifiers used in the datasets and in the writing up of the findings. In addition, any future reports provided to participants, and any future publications will include the de-identified alphanumeric codes. Furthermore, as a practitioner and a researcher I am bound to confidentiality, privacy, and respect of any individual I interact with on a professional basis. I have a "duty of care" (Robins 2015, p154) to my respondents that their participation in my study not provoke any stress or discomfort, or any risk greater than they may face in normal life. I rigorously respected this duty throughout the course of my fieldwork.

Additionally, a risk assessment was completed. The cities where fieldwork took place presented hazards which were mitigated by awareness and planning. Practices of increased self-awareness, use of radio taxis at night, avoiding dangerous situations were used, joined with initial scoping of the areas through learning from locals which areas to avoid and appropriate customs. Other hazards were controlled via measures such as drinking only bottled or boiled water, wearing a hat and sunscreen and keeping hydrated. While before departure I completed all recommended vaccines. To minimize emotional risks such as loneliness or anxiety, I prepared my virtual support network which included family, friends and my supervisors, and used yoga and exercises as coping strategies. Through a more official route, I advised the five local embassies and the foreign ministry of my dates and places of travel. Lastly, I received support from the local Alzheimer's associations by way of advice and suggestions.

## Consent from Participants

Verbal informed consent was selected for this project because of the cultural and socio-political context which could have influenced an individual's willingness to



sign papers and/or be audio recorded as noted in the Canadian Sociological Association's Statement of Professional Ethics (2012) point number 21:

"Generally, signed consent forms are the norm in social research, but there are exceptions. While obtaining a signed consent form will often serve to verify informed consent, in the study of cross-cultural contexts, illegal activities or politically sensitive settings, it may be difficult, impossible, or culturally inappropriate to obtain knowledgeable and voluntary (let alone written) consent from everyone in the field setting. Sometimes the requirement that one obtain signed consent forms from everyone studied may violate anonymity and actually create risks for some groups of participants. Therefore, the signed consent form may be inadequate or inadvisable in certain circumstances, in which case the researcher should employ culturally appropriate methods to allow participants to make ongoing decisions to participate or to withdraw from the research process."

Support for verbal consent is also provided by Brijnath (2014 p.29) in her experiences interviewing in a developing country:

"(...) while people were happy to give verbal consent, there was a profound distrust of written consent. Irrespective of their education and life experiences, people did not want to sign the consent form. None of the families and few key [care] providers agreed to sign. The documents were perceived as threatening, with potential legal ramifications. (...) Participants unwillingness to sign consent forms also highlights different notions of consent and researcher-participant relations as compared to [developing] countries."

Creed-Kanashiro (2005) and Hyder and Wali (2006) also recommend flexibility in documenting written informed consent when conducting research in developing countries, and allowing for alternatives such as verbal and/or community informed consent practices.

Informed consent to participate was requested from families with dementia verbally when scheduling to meet the researcher for the interviews. Following a verbal consent process method, based on Dewing's Process Consent Method (2007), and approved by the university ethical board, verbal informed consent was obtained again at the start of interviews and the background of the person with

dementia was investigated as to capacity and idiosyncrasies. Dewing's Process Consent Method (2007) consists of five elements:

- 1) permission to access the individual
- 2) basis for capacity to consent
- 3) initial consent
- 4) ongoing consent
- 5) feedback/support

The protocol applied in this study began with requesting permission for the interview and permission to access the person with dementia from the family. A basis for capacity of the person with dementia to understand and consent to being interviewed was first established from the family. If the individual was subsequently deemed by the researcher to not have capacity, anything the individual said would be kept confidential.

At the start of the interview I read the information sheet (and gave the family a copy) and requested verbal consent from all participants by reading the consent form aloud. I assessed if the person with dementia indeed had the capacity to understand and consent. Verbal process consent was noted in the interview notes with date, time, and names of participants. Any new or late comers to the interview were to be read the information sheet and asked for verbal consent to participate, if appropriate upon their entrance, or at the earliest appropriate moment, or at the end of the interview process.

Verbal consent was repeatedly requested throughout the process. For example, after receiving a response to a question, confirmation to annotate the response and use it for the research study was asked. With specific regard to persons with dementia, during the interviews I remained alert in interpreting when the person with dementia was reluctant to participate, which I learned through my training and experience in working directly with people with dementia in their homes and managing a dementia unit. This practice is also noted by Brijnath (2014, p.31) "(...) people with dementia either consented or rescinded in their own fashion. They would either verbally or through their body language, indicate disinterest and an unwillingness to participate". At which point the interview will either end completely, or depending on the family, the person with dementia may be

transferred to another room, or any responses will be kept confidential from that point forward.

At the end of the interview, feedback was asked of the participants. Verbal consent was requested again to ensure any information the participants preferred to maintain confidential was noted. Any transition support from the interview back to a context of daily life was considered and provided, such as, in the case of the person with dementia, discussing the next activity such as the dinner menu.

On one occasion, the family consisting of a married couple and their daughter invited me to join them in the living room for fruit juice. We conversed about the circumstances of the husband's diagnosis and symptoms. He participated, chiming in his own feelings of frustration through comical anecdotes, with an underlying note of sadness. His wife and daughter assisted him in recalling events, in a general agreeable manner. When for a short time the husband moved to another room, the wife and daughter commented privately to me about their growing frustration in his obliviousness to his own symptoms and behaviours, and the lack of services. A second family interview was with a married couple, the husband living with dementia. We met in a garden where the husband could walk around freely and safely. He participated in most of the interview providing input and confirmation of the wife's recollections and about his symptoms. The wife explained how the little information she received had not helped her understand how to manage her husband. He was beginning to show loss of social norms, for example only wanting to dress in swimming trunks, spontaneously undressing, and wanting to walk continuously.

The final occasion a person living with dementia participated in the interview was in very different circumstances. I had been invited to join a geriatrician and his team on a home visit. This family had previously given permission to the care team for me to be present during the visit to the health care team. I describe this interview in more detail in chapter 6. For each of these interviews, the consent process was followed and in conclusion of the interview, consent to use the data collected was reconfirmed.

The aforementioned process consent was also utilized for participating organizations. Organizations providing services to families with dementia were initially contacted by the researcher via email with the proposed information sheet requesting participation. If the organization agreed to participate, the verbal consent protocol form (appendix E) was sent to them, and telephone or in person verbal consent was requested in addition to the nomination of a representative with which to schedule an interview. Successively, representatives were contacted to schedule an interview. These representatives were briefed about the study using the attached proposed information sheet and given the opportunity to provide verbal informed consent upon beginning the interviews. Consent was continually reassessed throughout the interview using the verbal process consent (Dewing 2007) and feedback was requested at the end of the interview. Consent and any feedback, were noted in the interview notes with date, time, and name(s) of interviewees.

## Data Collection

In this section, I will discuss how I collected my data. I will describe my fieldwork experience, how I completed the semi-structured interviews and in what context, and the strengths and limitations of this selected method of data collection.

### Fieldwork experience

As aforementioned, the data collection process began with interviewing the Alzheimer's Association of each country. I asked each organization to make a list of the organizations they communicated or collaborated with, with which they had a connection or relationship, or recognized as offering or coordinating services for older adults. As aforementioned in chapter 3, in this study a family was considered an organization. From this list, I was often offered contact persons' emails or direct mobile phone numbers. Without having been referred to a point contact person, I learned it would have been nearly impossible to receive any reply from most representatives of organizations. Next, I either sent an email with the

project information sheet attached, or I sent a WhatsApp text, commonplace, introducing the study, and myself requesting an email address where to send detailed information about the research and participation. Using this form of referral, snowball and reputation sampling as described in chapter 6, allowed for a high response rate. This rate decreased slightly at the time of scheduling an interview date and time, but proved more effective than cold contacting any organization.

Seventy-five percent of the interviews took place in the offices of the organizations. The others took place in cafes, events, or families' homes. The most laborious part of the sampling was laying the foundation for the interview: contacting, waiting, recontacting, requesting to schedule an appointment, waiting, scheduling. Completing the interviews was energy consuming because of their length, and the challenge of maintaining interviewees on track. The interviews proved to me that the grand majority of the interviewees were offered few opportunities to tell their stories, to discuss the challenges they met and their achievements. My interest in their work and their country was received as permission to share their journeys. The longest interview, four hours, was with a family living with dementia. From my experience, I deduced that neither families nor health and social care professionals were receiving support. The second lesson was the struggle of interviewees to remain focused on the questions being asked. For example, a question including a numerical Likert scale produced responses of endless anecdotes either to provide evidence of the response or to avoid providing a precise answer. In my view, these behaviours were partly dictated by the context in which the interviewees lived and worked which I will expand on below.

The guiding questions for the semi-structured interviews included items pertaining to the classification of relationships between organizations. I divided this category into three elements: type of relation, interaction and flow. The type of relation item was intended to prompt a spontaneous category for a tie between two organizations, which did not occur. The question I asked referred to the representative's organization and the organization nominated:

*"How are the two organizations related?"*

This question caused confusion for the majority of interviewees as to who I was referring to, which led me to specify that I was inquiring about the inter-organizational tie as opposed to any personal ties. My additional subtext was:

*“How is your organization linked/connected to organization X? Do you have an agreement to work together for example?”*

This precision clarified the information I was asking for and did produce unambiguous replies.

Amongst the providers of services for older adults, organizations that tailored either their services, or specifically provided services for families living with dementia were tagged. A direct question was not included in the interview guide, yet the information sheet describing my study was dispensed to each interviewee before our meeting and reiterated again at the start of the interviews. On that occasion, interviewees immediately admitted if they did not provide services for families with dementia, uncertain if I would still be interested in including them. I prodded for details regarding the services they did provide and if unknowingly, families with dementia could be recipients.

Further, on the semi-structured interview guide, for each connection an organization representative nominated, I asked the interviewees to rate that connection in importance, strength and influence. I requested a quantitative reply based on a Likert scale of zero to ten where 0 represented not at all important/strong/influential and 10 represented very important/strong/influential.

After explaining the values of the scale, the exact question I asked each interviewee was:

*On a scale of 0-10, how important/strong/influential is the connection or relationship between your organization and organization X?*

I repeated this question for the three tie attributes. To clarify, as I did for interviewees, rating was based on a subjective definition. I was never asked to define importance, yet occasionally interviewees requested more information about the meaning of strength and often they asked me to clarify influence. The criteria I offered for strength were based on a merged conceptualization of the

strength of ties. Granovetter (1973) defined the strength of a tie as the “combination of the amount of time, the emotional intensity, the intimacy (mutual confiding), and the reciprocal services which characterize the tie” (p.1361). His work focuses on interpersonal ties, and how small scale interactions are related to macro phenomena such as social organization. To purposefully apply the construct to inter-organizational ties I combine the above with a business relationship specific definition where strength consists of trust, commitment and relationalism (Hausman 2001). Hausman cites the term relationalism as the belief in the value of inter-organizational ties in contributing to the success and survival of an organization.

For the purpose of this study, strength of tie was defined as a subjective perception existing within the tie that could include any combination of amount of time, frequency, duration, intensity, friendship, trust, commitment and relationalism. Reciprocity was used independently, thus not included in the strength construct. Influence was outlined as a subjective perception of the amount, frequency or quality of impact of any kind two organizations had on each other.

The majority of the interviewees easily identified the importance of each tie, yet had difficulty rating the strength and influence. The fear of a low rating was ubiquitous and I found myself explaining during every interview that a low rating is not negative, rather a snapshot of reality, and does not infer blame on anyone. Several times, I witnessed interviewees state, facial expressions accordingly dismissive, that the two organizations were rarely in contact or worked together, yet they would rate the strength of the tie on a scale of 0-10, no lower than 3. In those cases, I would nudge the interviewee by asking if they were certain, which would enact a verbal brainstorm on the tie, and a reconsideration, which did not always change the final rating.

During the interviews, I employed a different set of energy consuming behaviours. As a geriatric care manager, I learned how to conduct interviews with families with dementia and employees, where notetaking and my memory were my means to collect data. It developed into a modality I used, where my observational senses are heightened: I observed the person(s) nonverbal communication and the

interactions between people; I observed the environment; I asked questions; I listened; I took notes; I remembered (Fox 2004). Simultaneously, I was apprehensive of taking too much time; I filtered through what was said worrying if I was collecting the right and enough data. The language also required extra concentration, as it was a third language and in every country, some terminology changed slightly.

This style of interviewing involved making sure I understood not just every word, but the hidden messages, the subtext, the sensations, attempting to capture the non-verbal. It was a state of focus that allowed me a level of recall greater than in any informal conversation. This modality was moreover beneficial for the interviewee, because they felt deeply listened to and less scrutinized by short notes in a small notebook. People living with dementia may feel suspicious during interviews, and I found that the less notes are taken, which they may not understand hence the suspicion, the more they feel at ease. The positive result for me was more data, more details, often undisclosed, because the interviewees felt comfortable and trusting.

## Impact on Researcher

The impact on me, the researcher, of performing the interviews, can be arranged into two main time intervals: before and after, the interview process was described above. Before the interviews, the process I described above of scheduling interviews felt more like a chase of participants, in an attempt to pin them down to confirm a date. I often felt uncomfortable insisting by writing and calling multiple times. The most complicated part of the interviews was without a doubt understanding the addresses and locating them. In all five countries, the capital cities are not clearly demarcated with building numbers and city streets. Addresses consisted of cardinal directions, distances, and physical markers, for example: 50 meters south of the southwest corner of the main road, the building with the black gate. Gratefully, taxi and Uber drivers had more of an understanding of the city addresses than I did, and were extremely polite and helpful. Although we regularly went to the incorrect building, had to inquire, try



other entrances, all the while keeping in check my anxiety of being assaulted or robbed or cheated and to be on time and be dropped off at the correct location. Indeed, except Panama, the other countries were too dangerous to travel with public transportation or walk, a part of the context I will discuss in the next section. Therefore, before even beginning an interview I roamed around buildings asking, often in vain where nobody seemed to ever have heard of such a person or office, searching, back tracking, circling, until I either serendipitously found a good Samaritan who guided me to the office or person I was meeting, or I called the person who proceeded to fetch me, or I eventually arrived on my own. In all cases, I arrived wearied.

Each interview left me light headed, after consuming a substantial amount of energy listening attentively. After the interviews, I still needed to use my decision-making faculties. I had to organize where I was going, what I was eating and where and how I would get there and home. Once home, the work of transcribing my notes and observation awaited.

In sum, the mental and physical impact of completing the fieldwork for this study was unexpectedly trying, yet the learning gained on research, fieldwork, and my own strengths and limitations, are invaluable.

## Context

*The cities are unsafe. Everyone tells me not to walk anywhere for the risk of assault. Not just robbery but people have guns and feminicidio is common.*

*Therefore, you cannot go anywhere. Only with a taxi. It makes me feel trapped.*

This entry from my fieldnotes was written in Guatemala but also relevant for El Salvador and Honduras, and went on to describe the people walking in the streets, usually only with backpacks or things in their pockets, to avert attention. Each city had its safe areas near important embassies or in gated communities. Guards

with pump rifles lined the streets, in front of and inside shops, malls, banks, restaurants. Costa Rica's capital San Jose was safe during the day, but at night, the same rules applied of taking taxis and being wary of potential assaults and robberies. Panama City, the capital of Panama, was instead very safe day and night, like a European city, people lined the walkways along the seaside and filled the streets of the old town until late at night. Police officers roamed on foot regularly in the old part of the city, and patrolled the rest of the capital diligently. Racism was widespread in the five countries. The colour of skin made a difference. The darker the skin, the more suspicious. In gated communities, darker skinned people, commonly the indigenous, were regularly stopped and asked for identification documents, while I, for example, was not. The darker skinned people made up the lower socio-economic classes, and were 'the help' of the higher classes, most commonly the mestizos, light-skinned people, mixed race with European. House cleaners, cooks, housekeepers, gardeners, guards, drivers, were the darker skin and/or indigenous people's jobs. They lived on the outskirts of the cities in small pueblos often without running water and electricity, and it took them up to 3 hours one way on buses to go into the city to work and back. The class divide was evident in each country. Yet it was treated as normal, everybody knowing his or her place. Most upper class frequented foreign universities, many in the United States, others in Europe, and most spoke English. In fact, the influence of the United States in the region was shocking. Fast food chains, even those seemingly having disappeared in the U.S., crowded the capital cities of Central America. Shopping malls were the preferred location of socialization, considering they were also safe. The native culture hung on desperately, in religious ceremonies, typical foods, and the indigenous peoples, to avoid complete burial under a blanket made by the United States.

Labelling a country as a developing one, must take into account numerous aspects, one of them being the physical structure of public works. Clean, running water and functioning sewage systems are possibly two of these types of public works. In Central America, toilet paper cannot be thrown directly into the toilets, it must be thrown into waste paper baskets or rubbish bins, to avoid them stopping up and overflowing (a common occurrence). Faucet water is not potable anywhere. It is contaminated with amoebas and parasites. A doctor I met claimed

that a large portion of the indigenous people were contaminated by their water unknowingly. Another enormous public problem was the garbage. Garbage was everywhere, on the streets, piled on the hills surrounding the cities, thrown on the ground carelessly. Additionally, sidewalks, where existent, were not maintained, broken, cracked, with huge potholes, making walking even a short distance a feat. Furthermore, buildings in general are decrepit, dilapidated, as I noted in my fieldnotes:

*Panama: The Ministry of Health buildings are falling apart, a mess, even more inside than outside. People lined up in the hallways sitting in chairs filling in papers one at a time with an aide of some sort. It is like post war - where everything has been destroyed and there are few resources.*

The environments of the capital cities bred feelings of tension, fear, and vigilance. Nevertheless, the people were kind, hospitable, soft spoken and passionate.

Additional fieldnotes describe local contexts:

*In El Salvador, it is people not institutions that count. Each works separately. There is very little collaboration. Each organisation complains that the other organizations do not do anything. Each organization is out for itself.*

*There is a sense of instability where one government puts a program into place then the next government takes the funding away or the program itself.*

*Here in Honduras it is a bit of a mess. The political status changed many things and associations do not function and people are against each other and do not want to work together. A lot of personal friction. It is interesting that so much is on a personal level. Honduras has some decentralization in the health system as it has 3 big cities, where the G and E have only the capital city which is the centre of everything and only hub. In addition, decentralization is shown in the municipalities, which have autonomy in developing, and implementing the programs, they feel necessary for their populations. The coup in 2009 changed many things, polarized the nation on macro levels but also on meso - in associations, institutions and on*

*micro levels - in families - divorces for political differences. The most recent re-election of the president, which many deemed illegal, furthered the divide. This made working very difficult if not impossible where boards of directors were so divided nothing could get done. It was impossible to be impartial, unpolitical. This is what I have been told. People could not leave politics at home.*

*Costa Rica is so medical it feels almost antiquated. Repeated often to me was that if organizations are not obligated to collaborate they will not. Costa Rica has a high reputation in the region for being different, less corrupt, more economically stable, yet it does not seem true. My feeling is that here the defects are hidden. People in Guatemala, El Salvador and Honduras advised me that CR had a fantastic health and social care model, that it was much better than theirs was. Others (including lay people from CR) commented that CR hides their negative aspects to maintain their level of tourism, their appearance as the Switzerland of Central America". I do not find much difference with the other CA countries. Actually, it appears even more fragmented.*

*In Panama City, the smell of melting garbage is everywhere and it rains a bit almost every day so the smell becomes pungent. The smell of mould and humidity permeates everywhere. Sidewalks barely exist. Ghost buildings and skyscrapers, and traffic is congested at all hours. It is quite disorganized. People do not answer emails, or messages. They say yes to meeting but do not follow up and do not use official emails. No websites, some Facebook pages, but not updated. Many have more than one job so do not put all of their time into their work in older adults. People talk about events without addresses, not knowing start or finish times, or what exactly will be offered. Perhaps word of mouth is the most commonly used method of sharing info.*

The context was laden with unsuspecting challenges, but there were also many facilitators. The preparation and planning of first contacts, accommodation and

language, as Binns (2006) suggests reduced stress and allowed me to concentrate on gaining participants and on navigating the challenges. The risk assessment included in the university ethical approval process was an optimal checklist and reminder for travel insurance, vaccinations, contacting consulates, and regular receipt of local security updates. As I stated above, my own skills and personality traits built on my experience traveling and familiarity with multiple ethnicities, cultures and languages was undeniably an asset. Additional facilitators on site were fostering new friendships and the technological capacity of keeping in touch with my family, friends and supervisors. Regular breaks to enjoy local food, cultural events, the tropical weather, and the sites, regenerated me. I can now confirm that the memories, of this fieldwork will stay with me forever (Binns 2006), as will the memories of the time spent reflecting and strategizing on how to construct the data I collected.

### Construction of Data

In this section I will describe how I organized the data I collected through the interviews in preparation for analysis.

I transcribed my written notes from my notebook and my observations onto my personal laptop throughout fieldwork. This allowed me to download my brain's memory and free up space for the next interviews, as well as maintain my data organized from the beginning that proved an excellent decision at the analysis phase.

I transposed the responses of the interview guide questions onto excel, using one excel workbook, containing one sheet per country. The first column of every sheet contained the interviewee's organization's name abbreviated, the second column the organizations they nominated. This created a simple table displaying the interviewee and nominated organization and on the same line the responses to the interview guide items, see an example in Table 4.

Once completed fieldwork, I had five sheets like the example above that included every interview completed, for every interview all of the ties claimed, and the

relative attributes of the ties. These notes were the raw data of this study, the soil where to plant my thesis, and I treated them as such making multiple copies. Any observations and personal notes were written onto blank documents as free text. In hindsight, I feel that I could have structured this task to be more efficient.

Table 3 Snippet from fieldwork data 2018 workbook

Interviewee	Nominated	Relation	Interaction	Flow	Importance	Strength	Influence
AA	F1	client	dementia orientation, help to manage at home	assistance, info, payment	10	8	8
AA	F2	client	support group, psycho-emotional support	references, participation in celebrations	10	10	10
AA	F3	client	communication about mom	info of mom	10	7	8
AA	P1	medical consultant	agmt 50/50 consults, lectures for diploma, pt.instructions, collaboration w/ centre's pts.	info, knowledge, influence	10	10	10
AA	U1	agmt education, economic	knowledge/infrastructure for diploma, Alz awareness	info, influence	10	10	10
AA	U2	educational	facilities, patients for diploma practice	info	10	7	7

My knowledge and experience of fieldnotes was limited, and I did not find comfort in the task, rather it weighed on me as tedious extra work. The notes I did take, I kept in a separate folder planning to use them, as I have, for context descriptions in the writing of this thesis.

## Data Analysis

In this section I will outline the process I followed in the analysis of the data consistent with examples from similar social network analysis studies (Blanchet and James 2011, 2013, Davis et al. 2012, Nicaise et al. 2012, Provan and Milward 1995, Morrissey et al. 1994, Rosenheck 2013, Raeymackers 2013, Wang et al. 2016, Milward and Provan 1998, Glasby and Dickinson 2014).

### Preparing for Analysis

The steps to preparing for analysis consisted in organizing and categorizing the data. The first step I took to prepare the data I had collected was to clean it and check it. I verified the data I had entered into my computer by checking my written notes, cleaning up spelling errors, or missing or incorrect entries. The next step was to separate the data into categories. The categories were based on the interview guide and one excel workbook was created for each: type of tie, flow, exchange, and strength. The Likert scale responses for importance, strength and influence were grouped together by scores after separate analysis. Scores 0-3, 4-6, and 7-10 created the strength of tie category which consisted of the three dimensions of strength. One excel sheet was created for each country, for each individual category workbook.

### Analysing Node and Tie Attributes

The first analysis completed was the categorization and anonymization of the organizations, or nodes. Anonymization of the organizations followed the examples of the most influential studies in the literature (ibid) where interorganisational evaluations used types of organizations to categorise and anonymize. This analysis process to find and group the types of nodes to facilitate anonymization is described in Chapter 6, and resulted in nine types of

organizations emerging in all five countries' systems: Alzheimer's association, families, care homes, government, hospitals, non-profits, private, social security, universities. I proceeded to use an alphanumeric code to symbolize the type of organization and the number of that type within that country.

The aforementioned studies that the process of analysis for this study was based on, used predominantly quantitative data. Because the interview guide items types of relation, interaction, and flow were open ended, producing personalized yet short one or two word answers, thematic coding framed the analysis of these responses.

Thematic analysis is a method for identifying, analysing, and reporting patterns (themes) within data (Braun and Clarke 2006). The aim was to gather a thematic description of each data set, to understand the predominant or important themes. Based on the guidelines provided by Braun and Clarke (2006) thematic analysis was conducted. The themes emerged from the data, thus constituting an inductive approach, based on a semantic level explicitly taken from the data. A critical realist lens also framed the thematic analysis, in accordance with the previously outlined general epistemology of this study, where interactions are subjective as are their attributes, therefore language expressed the experiences of the interactions. Yet concurrently, these experiences are measured objectively through this analysis of the interactions.

The step by step guide (ibid, p87) was followed to ensure a quality analysis:

1. familiarizing with the data - transcription of data, reading re-reading immersing in the data
2. generating initial codes - data driven
3. searching for themes - in the codes
4. reviewing themes - do they reflect meaning of data as a whole
5. defining and naming themes
6. producing report - final analysis

Coding was a method of finding similarities or repeated responses, and grouping them together. Beginning with relation, I printed the Tables by country and used



colour coding and letters to group themed responses. The process was repeated for the three categories types of relation, interaction, and flow. The details of these processes such as the reviewing of themes and the results are explained in chapter 6 in the respective attribute sections.

The data collected was sorted into six distinct parts based on the items in the interview guide and/or the literature, each an attribute of the nodes or ties: types of nodes that are in the networks, types of ties that exist between the organizations, reciprocal ties where both nodes nominate having a tie with each other, the strength of the ties between the nodes, what is exchanged (interaction and flow) among the nodes, and dementia specific ties. A sub-attribute also emerged: multiplex ties within the exchange category, consisting of organizations that reported ties with more than one type of exchange, named a multiplex exchange tie. The analysis process and the findings of these node and tie attributes are discussed in detail in chapter 6.

#### Analysing Network Properties

In preparation for the analysis of the network measures, completed through the specific software Pajek and UCINET, new excel tables had to be compiled, which included only the alphanumeric codes of the organizations.

For each network that emerged from the analysis of the five main categories of ties: type of tie, type of exchange (interaction/flow), reciprocal ties, strength of tie, dementia specific ties, a matrix was developed. The matrix built onto excel sheets consisted of a first column, the interviewed organization code and a second column, the nominated organization code. This resulted in excel sheets which were then converted into SNA software, Pajek and/or UCINET, type files to be analysed. Each sheet represented a network; therefore, a sociogram, or web, was also created for each. As described in detail in chapter 7, the files were used to analyse four different network properties for each network, as stated above in the network analysis section: density, centralization, E-I index, and QAP correlation.

## Missing data

One other part of the analysis was considering the missing data. I was able to secure replies in sixty-one of the sixty-eight interviews. Although in most cases the interviews would end with the questions, after long descriptions of context, rather than be the focus of the conversations, I managed to minimize missing data. On two separate occasions, once in Guatemala another in Panama, the interviewees had engagements, which concluded the interviews before I could ask the six questions of the interview guide. Both of these interviewees took the time to reply to the questions electronically, and our virtual conversations included the above-described dialogue regarding definitions of strength and influence. An important note is that there is no missing data for the strength of ties items, nor for the exchange items. Where nothing was claimed to be exchanged in a tie, the data is not missing, the finding is precisely that nothing was exchanged which in fact emerged as a distinct, albeit small, category.

## Data management

In accordance with ethical requirements and university data management procedures, the data collected was stored on secure, password protected servers, my personal computer to which I alone had access, and the cloud provided by the university. My handwritten notebooks were always kept on my person, and in a locked cabinet in every residence and finally in the university.

## Conclusion

In this chapter, I discussed how my epistemological position and the methodologies selected framed this study. Through a critical realist stance, the ties between organizations were viewed as social constructions that can also be interpreted and measured using social network analysis. I also discussed and justified collecting data using semi structured interviews that offered the opportunity for personalization and adaptation, through open conversations, both requisites for interviews in complicated contexts, described subsequently. I

outlined the research design explaining how organizations providing services connecting with each other create ties that form structures and patterns, which are classed as networks. Measuring specific properties of these networks led to an evaluation of the level of integration of the older adult and dementia service systems.

In the next chapter, I will depict the Central American context as a region, and that of the five individual countries included in this study. I will also outline the regional and national policies in place protecting older adults and people living with dementia.

# Chapter 4: Central America

## Introduction

This chapter will provide an overview of Central America as a region, and individual national perspectives, offering context to the research. Context is important as it presents a number of variables that can influence what is directly being studied (Bate 2014). In this specific study, the variables could be barriers or enablers to the inter-organizational interactions structuring an older adult and dementia service system.

The first section provides a brief history of the formation of Central America as a region of autonomous countries post colonization. A second section will look at demographic and cultural similarities and differences between the countries, what unites them and what are barriers to their cooperation. Next, national health systems and older adult legislation are discussed. Lastly, I will describe the strategic organization for integration and collaboration of the region as part of the greater Americas and Latin American regions, and the integration of the Central American countries.

## The Birth of Nations

Geographically Latin America comprises Central and South America. A more accurate term is Iberoamerica, as people of the Iberian Peninsula colonised Central and South America. Seven countries make up Central America: Guatemala, Belize, El Salvador, Honduras, Nicaragua, Costa Rica and Panama. The history illustrated subsequently is taken from two principle sources: The companion to Hispanic Studies by Davies (2002) and Modern Latin America by Skidmore et.al (2010).

The Maya Empire began about 2000 BC in Mexico, and occupied Guatemala, Belize and parts of El Salvador and Honduras. The Aztec Empire formed more

than 3000 years later in the same areas in the late 1300s AD. In 1501, Spaniards reached Central America where natives lived in independent, stable trading communities. In 1519, Hernan Cortes, a Spanish conquistador crushed Tenochtitlan, the Aztec capital in what is present day Mexico. In 1521 the Aztec empire fell. This marked the beginning of the conquest of the New World by the Europeans. The Spaniards took control of Central America founding colonies, although since it was not a source of wealth like South America, it was not the primary focus of the Spanish crown. The variety of native cultures required conquest and invasion to take place in phases and a new government was implemented after every conquest. The Central American isthmus belonged to the Viceroyalty of New Spain until the early 1800s. During the colonial period, the region's population was only 4% white which meant, Spanish or Creole, of European descent. The rest of the population was a mix of 65% Indian and 31% ladino, a term for mixed racial backgrounds that included African descent. In 1813 Mexico declared its independence from Spain and in 1821 Central American landowners, Creoles, appropriated the isthmus from Spain proclaiming the Act of Independence of Central America, and joined the First Mexican Empire until 1823. To declare independence next from Mexico, the United Provinces of Central America was formed in 1823 and included Guatemala, El Salvador, Honduras, Nicaragua and Costa Rica. Panamá had become a department of the Republic of Colombia after independence from Spain. Belize remained under British rule until 1862 when it was officially instated as a British Crown Colony. The United Provinces of Central America split into separate nations in 1838. Following a civil unrest, El Salvador declared itself a republic in 1841, Panamá became independent of Colombia in 1903 and Belize became an independent republic in 1981 (Booth et al. 2010).

The trade structure with Europe, developed by Spain, endured the formation of the autonomous countries. What suffered was the region's unification. Economic problems initiated even before new governments were established, from the costs of fighting for independence and equipment. Central American countries were founded on debt and became promptly enslaved to foreign lenders, especially Britain, and continue to endure this bondage. Men of notable military capabilities of any ethnicity soon contrived a route toward higher social rank, even political

leadership, which led to the historic and continuous power struggles between civilians and military dictatorships. For natives, it was indifferent which party held leadership, they were not protected, and because they themselves had remained indifferent to political interest and fighting (Williams 2002). From the mid-1800s, the native populations suffered devastating losses of lives and land as governments aimed at integrating with the world economy.

Central American states were kept under economic control by Western European industries, which surpassed them in manufacturing goods with innovative machinery and tools that new nations imported heavily. The fundamental factor influencing the new economies in the 19<sup>th</sup> century was the European concept of free trade, a principle underlying even contemporaneous liberalism. Free trade resulted in an unequal ratio of import to export for Central America, and by choosing to concentrate on agrarian production and plantation societies; they portrayed an unintentional, metaphorical admission of submission. Lack of confidence in their own ability caused new governments to recruit European migrants for their labour force. Central America developed a culture of inequality, of pronounced lower and upper classes, a clear distinction between luxury and poverty.

The region is the poorest and most unequal region of Latin America and the most violent region of the world (De Redaccion 2015, Cruz 2015, UN 2019). The main exports are coffee and bananas, of which are largely controlled by U.S. corporations that continue to thwart Central America's development by investing and controlling (Skidmore et al. 2010). Through the end of the 20<sup>th</sup> century, Central America was torn apart by civil wars, politically thus socially unstable and financially run aground and its health systems reflect this (Barrett 1996).

Central American governments signed a peace treaty in 1987 taking a fundamental step to ending the civil wars in Guatemala, El Salvador and Nicaragua, which led to national peace agreements within ten years (Kurtenbach 2007). According to Kurtenbach (2007), two million Central Americans fled their homes and 300,000 lives were lost in the wars. In 2014 the Latin American and the Caribbean states (CELAC) declared themselves a 'zone of peace' (Kurtenbach 2019). Post-war effects on the socio-cultural national foundations, legacies of

violence, and external economic and political influences, haunt the region's peacekeeping efforts (ibid). These effects are reflected and discussed in the findings in chapters 5 and 6.

## Similarities and Differences

Similar historical and cultural characteristics connect the seven countries of Central America, which are also distinguished by social, environmental, political and economic diversity and health care provision (Monge et al. 2010, Saraceno et al. 1995). The World Trade Press published a Society and Culture Report (2010) for each individual country of Central America describing the basic cultural norms, which I compared in Table 5. Christianity and Roman Catholicism are the predominant religions throughout the isthmus. Cultural traditions are shared across the countries, such as a girl's 16th birthday marking her passage into womanhood. The celebration transforms into a struggle, once a woman enters the workforce, also shared cross nationally and evidenced by disparate salaries between the sexes, with women earning between 20% to a staggering 66% less than their male counterparts, according to the World Trade Press reports (2010). Comparatively, the retirement age is equal for both genders only in Guatemala and Nicaragua. Traditional Catholic family roles mixed with indigenous traditions of honour impose strict social norms on respecting and safeguarding older persons. Filial piety is the norm and implies all-inclusive filial care and support, for example, in El Salvador; the National Family Code obligates familial care. Nevertheless, many of this study's interviewees, representatives of older adult service providers, claimed that abandonment of older adults was a commonality. Due to expenses, many families cannot afford to maintain their older adult with them. Accounts from care homes narrate families dropping off older adults and providing false contact information, never to return. Abandonment is a form of elder abuse, and a social and economic phenomenon present in the region (Dong et al. 2008, Lachs and Pillemer 2004, Vaswani 2001).

Colonialism imported and forced Spanish to be the common language. However, it is not the only official or spoken language. Pre-Hispanic Amerindian cultures

and social structures survived (Davies 2002). Some indigenous dialects survived and scholars are working on categorizing them.

Table 4 Intra-regional similarities and differences

	Guatemala	Belize	El Salvador	Honduras	Nicaragua	Costa Rica	Panama
<b>Predominant Religion</b>	Christianity	Christianity	Roman Catholicism	Christianity	Christianity	Roman Catholicism	Roman Catholicism
<b>Languages</b>	Spanish, English, Quiche', Cakchiquel, Man, Tzutuhil, Quekchi', Pocoman, 40+ others	English, Spanish	Spanish, English, Pipil, Nahuatl, Lenca	Spanish, English, Misquito, Pipil, Lenca	Spanish, English, Misquito	Spanish, English	Spanish, Chinese
<b>Quinciñera</b>	Yes	Yes	Yes	Yes	Yes	Yes	Yes
<b>Divorce</b>	Yes	Yes	Yes	Yes	Yes	Yes	Yes
<b>Salaries F to M</b>	50-75% less	less	30% less	60% less	≤ 50% less	66% less	20-35% less
<b>Retirement Age</b>	63	60-65	55F, 60M	60F, 65M	60	59F, 61M	57F, 62M
<b>Care of Older Persons</b>	Filial piety and care	Filial piety and care	National family code requires familial care	Filial piety and care	Filial piety and care	Filial piety and care	Filial piety and care
<b>National Law Protection of Older Adults</b>	1996	2002	2002	2006	2010	1999	2016
<b>National NCD Dept.*</b>	Yes	No	No	No	Yes	No	Yes
<b>National NCD Protocols*</b>	No	No	No	No	Yes		Yes

World Trade Press 2010, www.americacentral.info , \* World Health Organization 2012

F: female, M: male; NCD: non communicable diseases

English has also made its way into the isthmus through trade and tourism; it is the official language of Belize. Panama had a flourishing Chinese migrant community making Chinese the second recognized language. Misquito is Nicaragua's third language and is also spoken in Honduras, which together with El Salvador count three different indigenous languages, both Pipil and Lenca, also Nahuatl in El Salvador. Guatemala accounts for the most indigenous populations in Central



America, where Quiche`, Cakchiquel, Man, Tzutuhil, Quekchi`, Pocoman and 40 plus other languages are spoken (Americacentral 2019).

Central America is home to approximately 180 million people. Guatemala is the most populated country and Belize the smallest (Table 6). The other countries range between approximately 4 to 10 million people. Adults over 65 years old make up between 5-10% of Central American countries (UN 2019).

Table 5 Population in Central America

	Central America	Guatemala	El Salvador	Honduras	Costa Rica	Panama	Belize	Nicaragua
<b>Population* (thousands)</b>	177,587	17,581	6,454	9,746	5,048	4,246	390	6,546
<b>Pop &gt; 65 y.o.*</b>	7%	5%	8%	5%	10%	5%	5%	8%

\* UN population prospects data 2019, highlighted: countries included in study

In the literature, Central America is interchangeably categorized as a low to middle income and developing region (Ferri and Jacob 2017, Prina et al. 2019, Walker and Paddick 2019, Prince et al. 2004). The World Bank (2020) categorizes Panama as a high-income country, Guatemala, Costa Rica and Belize upper middle-income countries and El Salvador, Honduras and Nicaragua as low-income countries. The United Nations Human Development Reports (2019) list all seven Central American countries as developing, presenting statistics on the low levels of education, highly prevalent poverty and violence rates. Following the literature, I will use the labels LMIC and developing interchangeably throughout the thesis, because the discrepancy of the categorisation of the individual countries is based on economic criteria by the World Bank, while the human development reports use combined socio-economic data. This said, the higher economic statuses of Panama, Costa Rica and Guatemala will be referred to when relevant to findings later in the thesis. Although Panama, Costa Rica, and Belize have less internal diversification and more economic development, the region as a whole is very poor (UN 2019), and culturally, the seven countries share traditions and social norms, as well as the primary language.

## National Health Systems

Through a report on Latin American health systems published by the Spanish Social Security Institute (2010) and articles published in the bi-monthly interdisciplinary journal *Salud Publica de Mexico*, I have compiled a general description of the national health systems of the five Central American countries included in this study.

The national health systems are generally polarized into the public and the private sectors. During fieldwork, I observed the difference between the two sectors and how racial and socio-economic divides were most evident in healthcare. The public facilities appeared archaic and crumbling compared to the luxurious private institutions. The people that lined the corridors and packed the waiting rooms of the public hospitals were dark skinned, small statured, native looking, as opposed to the few white, European looking visitors, hastily assisted in the private clinics.

In El Salvador, The Social Security Institute, the Military Health Magistrate, the Solidarity Health Fund and Ministry of Public Health and Social Assistance are the public sector funders, while the private category includes private providers and non-profit and non-governmental agencies (Acosta et al., 2011). In Guatemala, the public sector is made up of the Ministry of Public Health and Social Assistance, Military Healthcare, and Social Security. Non-governmental organizations and private practitioners offer private assistance. Interesting to note that senility was listed on the Informational Platform of Social Integrity as the fifth cause of death for both men and women in 2009 in Guatemala (Becerril-Montekio & López-Dávila, 2011). Yet no legislation relative to dementia is in place. Programs to expand coverage for basic services and drugs targeted rural populations (Becerril-Montekio & López-Dávila, 2011, Rubio & Ugarte, 2014). The public sector of Honduras' health system is divided into the Health Secretariat and the Social Security Institute, which provide services to approximately 60% of the population (WHO 2013, Bermudez-Madriz, 2011). Private insurances, or out of pocket

payments to private clinics and hospitals make up about 5% of the health services, while 17% of the population doesn't have access to services (Bermudez-Madriz, 2011). Panama's national health system is managed by two main institutions: the Ministry of Health and the Social Security Fund both divided into 14 regions to serve the public. These institutions cover 90% of the population, leaving out some indigenous and rural residents due to geographical and economic hindrances (WHO 2014). Costa Rica's public sector is dominated by the Social Security Office and includes the Social Development and Family Assignment Fund, which oversees the Ministry of Health that branches regionally (Saenz et al., 2011). Private insurances and the National Insurance Institute make up the public sector, though the National Insurance Institute operates in the private sector as well (Saenz et al., 2011). The social security institutions present in every country were governmental entities yet administered and operated independently. These presented the most challenges to access, resulting in four interviews of the 10 social security organizations included in the study.

From the organizational charts provided in Giedion et al.'s report (2010), the systems are strategic, some with more complex funding paths and multiple public providers (Block and McQuire 2008), but all public sectors rely on the triad central government, employers, and employees, while the private sectors are funded by the dyad out of pocket contributions and insurance premiums. Interesting to note, Guatemala is the only country where the presence of non-governmental associations is featured in the organizational charts, and they are incorporated into the private sector. Coverage is ranked high for basic health services in Central America, but the systems are determined financially unstable, sharing problems of inequity (Block and McQuire 2008). This inequity was confirmed during fieldwork, with a noted stark difference between the public and private institutions in terms of physical aspects and the clientele described in the next chapter.

Barrett (1996) describes a widespread U.S. influenced culture of individualism, commerce and paternalism in Central America. Historical notions and impressions from a report by International Democracy Watch (2011) on regional integration, discussed subsequently, paint the same picture.

## Legislation for Older Adults

Laws specific to protecting older adults' rights were developed beginning in the 1990s in Central America. These special laws are extremely valuable as they allow the state to organize action in favour of older adults, and establish limits and possibilities for public authorities to exercise older adults' rights (Huenchuan 2011). As of 2016, every Central American country has included in their constitutions laws regarding older adults (Table 7). From a comparison of these legislations by Huenchuan (2011), commissioned by the Economic Commission of Latin America and the Caribbean, a United Nations sub-institution, I summarize their chief aims.

Table 6 National Laws for Protection of Older Adults

2016	Panama	Ley 36
2010	Nicaragua	Ley del Adulto Mayor
2006	Honduras	Ley 199
2002	Belice	Política Nacional para las Personal Mayores
2002	El Salvador	Ley de Atención Integral para la Persona Adulta Mayor
1999	Costa Rica	Ley 7935
1996	Guatemala	Ley de Protección para las Persona de la Tercera Edad

Costa Rica, Honduras and Panama recognize generalized special protection for people over 60 years of age. Guatemalan national policy guarantees protection to older people, specifically a right to nourishment, health, education, security and social provision. Panama protects the physical, mental and moral health of older people and guarantees their right to nutrition, health, education, security and social provision. The state of El Salvador is obligated to care for the destitute regardless of age or disability. Panama protects against age discrimination in employment, and Guatemala established a fair treatment policy for older adult workers. Furthermore, in Guatemala the death penalty is prohibited for older adults over 70. Huenchuan (2011) indicates that the special laws for older adults are not homogeneous resulting in states applying only the minimal standard human rights. As will be discussed in chapter 5, the findings show human rights institutes with departments dedicated to older adults in Guatemala, El Salvador, and Panama.

The number of people with dementia in Latin America and the Caribbean will increase from 7.8 million in 2013 to over 27 million by 2050, yet most countries in the region lack specific dementia policies, according to Brito-Aguilar (2019). As aforementioned, it is estimated that the number of people with dementia will increase especially in Central America (Prince et al. 2015, Stokes 2015). Costa Rica was the only country of the region that had developed a national dementia plan as of 2014, and El Salvador had a plan awaiting ratification. Currently, the Alzheimer's Federation has a regional office, Alzheimer Iberoamerica, and a country office is present in each country of the isthmus, not all of which are operational as will be described in chapter 5. Neither older adult care, nor dementia are mentioned in the health care systems literature. Public care centres are indicated in the World Trade Press country reports (2010), but dementia specific information is absent.

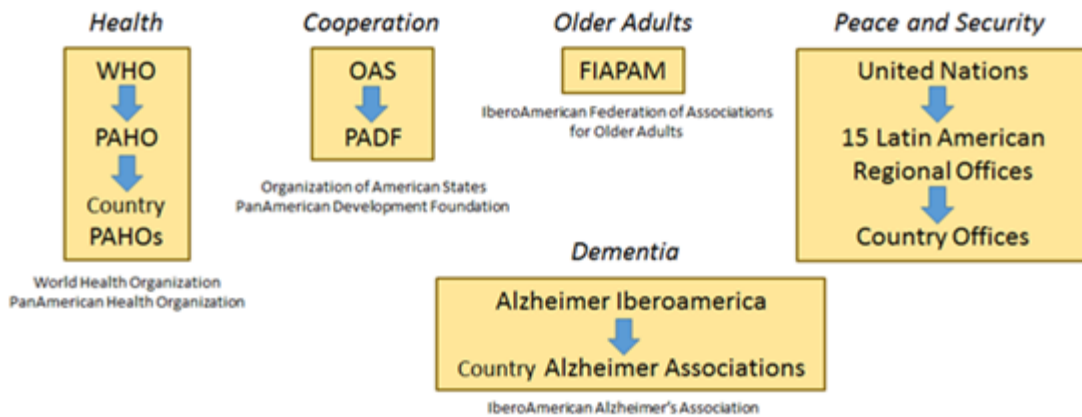
## Inter and Intra Regional Integration

Central America partakes in the inter-regional cooperation of both the Pan-American region comprising North, Central and South America, and the Caribbean, and the IberoAmerican region that includes Central and South America plus the Iberian Peninsula. On an inter-regional level, five major organizations lead the integrative processes for health, cooperation, older adults, dementia and development (Chart 3). The Pan-American Health Organization (PAHO) was founded in 1902, before the World Health Organization (WHO), and is now a WHO regional office with collaborating PAHO centres present throughout the Central American territory. PAHO centres lead strategic collaborative efforts to promote equity in health, combat disease, and improve the quality of the lives of the peoples of the Americas (PAHO 2017). The Organization of American States (OAS) was established in 1948 in Washington D.C., and constitutes the main political, juridical, and social governmental forum in the Hemisphere, counting 35 independent states of the Americas (OAS 2017). The Pan American Development Foundation (PADF) is financed by the U.S. Agency for International Development, the Inter-American Development Bank, the Social Progress Trust Fund, the OAS,

and corporate and private donors (PADF 2006). It was created in 1962 as a partnership between the United States and Latin America.

There is also inter-regional integration and cooperation for support and advocacy for older adults of the IberoAmerican world. The IberoAmerican Federation of the Associations for Older Adults (FIAPAM the Spanish acronym of Federación IberoAmericana de las Asociaciones de Personas Adultas Mayores) extends the efforts of local, sectorial and national associations to an international level (FIAPAM 2012). Even though, institutional guarantee of older adults' special rights laws is missing, with no exact policies on how to implement those rights nor who, or which branch of government or institution is to put the laws into effect (Huenchuan 2011). The United Nations provides Latin America with 15 regional offices under various competencies, of which one-third are based on the isthmus, and various country offices. As outlined in the previous chapter, Alzheimer Iberoamerica is the regional centre of Alzheimer Disease International (ADI) and heads the country offices in each Central American country.

Figure 10 Inter-regional integration



At the regional level, the integration system was initiated through the Central American Parliament in the 1960s (Parlacen from its Spanish acronym of Parlamento Centroamericano) demonstrating the acknowledgement by leaders, of the connection between national and regional fortification (Papageorgiu 2011). Some noteworthy phases in the formation of the Integration System of Central America (SICA from its Spanish acronym of Sistema de la Integración

Centroamericana) were the addition of Panama in 1994, the creation of the social sub-system to combine social policies in 1995, and Belize joining in 2001. The SICA was analysed by the Centre for Studies on Federalism of the International Democracy Watch (IDW), and the report by Ioannis Papageorgiu was published in 2011. It concluded that national, over regional goals, and the lack of a long-term perspective proved that integration was stagnant. Furthermore, the permeating national reluctance to surrender some authority, regional adversities such as prevalent poverty and lack of democracy, state vulnerability and frailty, and foreign control, were all obstacles to regional integration. In concordance with Barrett's (1996) claim that each individual state has a responsibility before higher level coordination and cooperation, Papageorgiu (2011) confirms that, intra-regional economic and social differences continue to thwart integration progress.

The six major challenges that SICA faces, highlighted by the report, are: a complex institutional framework; coordination efforts; intra-regional integration secondary to U.S. dependency; national agendas dominating integration; and external forces such as natural disasters and border disputes. According to De Redacción, (2015) weak economic growth, sustained obstacles, international openness and insertion processes, depict sluggishness in the Integration System of Central America. The 21st century brought the entrance of civil society, via the Consultative Committee of the SICA. Composed of non-governmental organizations representing public views relating to regional integration (Papageorgiu 2011), the committee adds a thread of co-design in the strategy toward intra-regional partnerships.

In the specific field of dementia, the Alzheimer's associations of four Central American countries: Guatemala, El Salvador, Honduras, and Costa Rica, are members of the Iberoamerican Alzheimer's association, the Latin American regional office for the Alzheimer's associations, as mentioned in chapter 2. Every year a conference is held in one of the Latin American countries, where countries can share with and learn from each other's care models and practices. This is an important practice and indicator of intra-regional integration directly related to the provision of dementia care.

## Conclusion

Central America is a region, which has remained divided and chaotic since colonialism (Barrett 1996). It is made up of incomplete states with fragmented and undefined territorial presence (Cullell 2012). Regional integration has been deemed sluggish (Papageorgiu 2011, Lo Brutto and Salazar 2015). In the most recent intra-regional social integration strategy (SISCA 2016-2020), the objectives are not specific to particular groups or social services. Aims focus on developing standardized regional guidelines, intra-regional communication, and networks. From the literature, there is little confirmation of in country integrated health systems and no evidence of dementia service systems. The silver lining is the movement in support of older adults, both on regional and national levels. The desire to form an identity, and the traditions of community participation could be conducive to integration at local levels (Barrett 1996, Papageorgiu 2011, Saraceno 1995, Vazquez et al. 2009). Reflection on the findings in light of the specific contexts in Central America will be included in the next chapters.



# Chapter 5: Regional and National Services

## Introduction

This is the first findings chapter. Beginning with this chapter through chapter 7, the findings of this study will be presented. This chapter explains the findings of the services available and the organizations providing them in each country; the micro level of the five older adult and dementia service systems. The meso level, the ties between the organizations are defined in chapter 6. In chapter 7, the networks formed by the inter-organizational ties are presented.

This chapter offers a regional and a national perspective on the services provided to older adults and their families. Data on health and social care and support services for older adults in Central America are scarce. Here, in addition to a list of organizations, details of services offered in each country have been compiled. These findings do not necessarily provide an exhaustive list of service providers, but of those organizations that were interviewed or nominated. In the first section, through individual descriptions, comparisons across countries are made of the founding organizations providing services. In the second section, the idiosyncrasies of each country are described. Beginning with the organizations unique to a country's network, brief discussions about the national tones in the older adult sectors are presented, as well as a summary including a focus on the dementia specific spirit.

This chapter provides primary data on services available in the region, preparing the foundation of the networks, before undertaking the more detailed analyses of the ties between the organizations in the following chapter.

## Services in the Region

This section delves into the services present in the five systems. These services are provided by different organizations. Across countries, organizations with

similar purposes or providing similar services were found. Table 8 outlines the organizations by purpose, and in which countries they are present. In the table, the organizations are categorized by the number of countries a version of an organization is present in. Similarities of the systems are shown by way of versions of an organization existing in multiple countries. The patterns of how the systems are structured across countries are visible and are discussed in each subsection.

Although not operative in two countries, an Alzheimer's association was present in all five countries. As stated in the methods chapter, this was the first point of contact in each country. In addition, Table 8 shows that in all five countries a version of a commission on ageing was present, as well as families with dementia providing care, care homes, universities collaborating in providing services to older adults, and various ministries. In four of five countries, a dedicated hospital unit was present, along with memory clinics, a gerontology or geriatrics association, and municipality services dedicated to older adults. In three of five countries existed a commission of human rights department dedicated to older adults, a commission of persons with disability, and day centres. Two of five countries offered older adult integrated care centres. Panama had the least similar system to the other countries, while Guatemala and El Salvador had the most similar systems.

The pattern of similarity in the structure of the systems confirms that the foundation on a regional level, for systems dedicated specifically to the older adult populations, is in place. It also portrays a potential practice of using each other as examples. The system structure similarities could indicate partnership working at a regional level, where regional associations and standards within the ageing sector led to joint planning. Yet the lag in Honduras, Costa Rica and especially in Panama in keeping up with their neighbours shows a possible lack of accountability at the regional level, and/or low priority by those governments. In the following section, the service organizations will be described in subsections.

Each subsection describes the organizations present in a specific number of countries, following Table 8, beginning with organizations present in all five

countries. This section aims to highlight how organizations with akin purposes are structured and operate similarly, but also how they differ between countries.

Table 7 Organizations present in country networks

Org. Present	Purpose of Organization	GUATEMALA	EL SALVADOR	HONDURAS	COSTA RICA	PANAMA
In 5 countries	Commission on Ageing or Older Adults	CONAPROV	CONAIPAM	DIGAM	CONAPAM	not operative
	Alzheimer's association	yes	yes	not operative	yes	not operative
	Families living with dementia	yes	yes	yes	yes	yes
	Care Homes	yes	yes	yes	yes	yes
	Universities offering practicum with OA	yes	yes	yes	yes	yes
	Ministries	Culture/Sports, Health, Labour	Edu,Health, Labour	Edu, Health	Social Support, Social Protection, Women's Institute	Health, Social Development
In 4 countries	dedicated unit to Older Adults	yes	yes	yes	yes	no
	Memory Clinics	no	yes	yes	yes	no
	Gerontology / Geriatrics Association	yes	yes	no	yes	yes
	Municipalities OA dept	yes	yes	yes	yes	no
In 3 countries	Human Rights Commission of Older Adults	yes	yes	no	no	yes
	Commission People with Disabilities OA dept	not OA specific	not OA specific	no	no	not OA specific
	Older Adult Day Centres	yes	yes	no	yes	no
In 2 countries	Older Adult integrated care centres	yes	no	yes	no	no

yes = present in networks; no = not present in networks; not operative = present but not operating; OA = Older Adult

## Commission on Ageing

An important finding was that four countries have an active acting governing body that is designed to oversee services for older adults, in Panama it was not yet operating. Each is a form of a commission on ageing or of older adults. These commissions are evidence that following the implementation of the aforementioned national policies protecting older adults, further actions by governments to enact them were taken. Table 8 shows the five commissions, the year of inception, and the relative member associations. Each country's respective organization's translated title is provided in Table 8, along with the

original Spanish acronym. The Spanish acronym, followed by the Spanish title, will be written in the subsequent section, and then the Spanish acronym will be used throughout the rest of the section. Both in El Salvador and in Honduras I conducted interviews with representatives of the commissions. In the other networks, the commissions remained nominated nodes, while I didn't conduct interviews with them these organisations were identified in the networks of other organisations.

Table 8 Commissions on ageing by country

Guatemala	El Salvador	Honduras	Costa Rica	Panama
<i>TITLE OF COMMISSION</i>				
CONAPROV National Committee of Protection of Ageing	CONAIPAM National Council of Integrated Attention to Older Adult Programs	DIGAM General Directory of Older Adults	CONAPAM National Council of the Older Adult	DIAM Directive of the Older Adult Institute
<i>YEAR FOUNDED</i>				
2016	2009	2007	1999	2017
<i>MEMBER ASSOCIATIONS</i>				
Secretariat of Social Operas of the President's Wife	Health Ministry	Technical Committee	Office of the President of the Republic	<i>Not operative.</i>
Social Security Institute	Social Inclusion Ministry	Civil Society	Ministry of Health	
Ministry of Public Health and Social Assistance	Social Security Institute	All Ministries	Ministry of Public Education	
National Attorney General	Corporation of Municipalities		Ministry of Labour and Social Security	
private enterprise	civil society		Board of Social Protection	
nonprofit enterprise			Mixed Institute of Social Assistance	
Department of Regulation, Accreditation and Control of Health Facilities			Social Security Institute	
Alzheimer's Association of Guatemala			State Universities	
			Gerontological Association	
			Associations of Retirees	
			National Crossed Federation of Older Adult Protection	

Guatemala's CONAPROV (the Spanish acronym for Comité Nacional de Protección a la Vejez) maintains direct contact and collaborates with the World Health Organization and the Pan American Health Organization. They also engaged in developing the supervisory protocols of all types of care centres for older adults, and facilitated the opening of the first of a series of public day centres.

El Salvador's council is the CONAIPAM (Spanish acronym of Consejo Nacional de Atención Integral a los Programas de los Adultos Mayores). The council offered short courses for family caregivers, with the specific aim of avoiding to train domestic workers how to be caregivers. The fear of perpetuating exploitation of domestic workers prompted the CONAIPAM to focus training seminars on unpaid carers, and/or persons working only as caregivers.

In Honduras, the main governing body is the DIGAM (from the Spanish acronym of Dirección General Adulto Mayor,). The DIGAM managed government programs for older adults such as clubs, day centres, and 32 care homes of which 1 is public and 3 are subsidized. It was also the institute that worked on organizing and formulating older adult public policies such as criteria for care facilities and day centres, proposals and processes.

The CONAPAM of Costa Rica (from the Spanish acronym of Consejo Nacional de la Persona Adulta Mayor) formulated and executed public policies with the aim of quality of life for older adults.

Panama established the DIAM (from the Spanish acronym of Directiva del Instituto del Adulto Mayor). Although the directive members were sworn in, the institute had not yet been formed.

## Alzheimer's Associations

The Alzheimer's association was common to all of the networks; one was present in each country (Table 10). As aforementioned in the methods section, the Alzheimer's associations were the starting point in building the networks in each country. Each association differed in structure and operation, but all five were led by neurologists and medical professionals on the boards of directors, casting a biomedical approach on the aims of the associations and the services offered. Another common feature was the informality of the associations, because of lack of funds, none used a website, offered informative brochures, or maintained office

space appropriate to meet with families. Only in Guatemala, the association had secured a house in donation, which became the headquarters.

Table 9 Alzheimer's associations by country

Guatemala	El Salvador	Honduras	Costa Rica	Panama
<i>YEAR FOUNDED</i>				
1995	1994	2004 - 2009	1999	1995 -2017
<i>FOCUS</i>				
gerontological & biomedical approach	biomedical approach	biomedical approach	biomedical approach	biomedical approach
<i>FINANCED BY</i>				
donations pharmaceutical company(ies) caregiver diploma	donations pharmaceutical company(ies)		donations pharmaceutical company(ies)	donations pharmaceutical company(ies)
<i>SERVICES OFFERED</i>				
university practicum day centre geriatrician (priv) caregiver diploma national conference day events diagnosis dementia drugs prescriptions	university practicum seminars national symposium day events diagnosis dementia drugs prescriptions		seminars caregivers' house national conference diagnosis dementia drugs prescriptions	seminars diagnosis dementia drugs prescriptions

In Guatemala, the Association Ermita Group Alzheimer was founded in 1995. In 1996, Alzheimer's Disease International (ADI) accepted the Ermita group as a national Alzheimer's Association. The association offered a Day Centre, medical consultations with a geriatrician, a support group for family members, and the Diploma for Caregivers of Older Adults with Emphasis on Alzheimer's and Related Diseases. The Day Centre provided geriatric consultation, physical therapy, and occupational therapy to the participants. Staff included one permanent nurse and one permanent caregiver holding the Caregiver Diploma. The other caregivers were students of the Caregiver Diploma that complete their practicum hours working in the Day Centre. Students in physical and occupational therapy degrees of the University Galvez also complete their practicum hours working in the Day Centre. Participation in the Day Centre was based on sliding scale fees taking into

consideration families' needs. In terms of finances, the Association relied on donations, and income from the Diploma and the Day Centre. The Day Centre offered support to between five and 10 people living with dementia depending on the possibility for families to drop off and pick up their loved ones.

El Salvador's Alzheimer association was founded in 1994. The people who were managing it had personally witnessed how the health system was not prepared to deal with or understand people with dementia so became dedicated to informing the public and offering support. The association was based on a biomedical approach, deriving from the leadership of the board that was headed by a neurologist also head of the memory clinics. The Bayer laboratories offered financial resources. The association had a scientific committee of different medical professionals and offered medical presentations once per month, a national symposium, nutritional presentations, and day events. It became evident that the association had few connections with other members of the commission on ageing CONAIPAM. A written agreement with a private nursing school, which offered a free caregiver diploma, allowed the students to do their practicum with families living with dementia and members of the association.

The Alzheimer's association in Honduras was founded in 2004. After the political coup in 2009 many things changed in the country as stark polarization developed. The association suffered from this political divide, which affected the board of directors and the volunteers. Subsequently, following an subsequent election, again, the political climate changed and the board and personnel could not come together. The Alzheimer's association was not operating when I visited. The atmosphere of individuals involved was one of controversy. Without an agreement amongst the board members, no programs could be offered to the public.

In Costa Rica, the Alzheimer's association is named ASCADA from the Spanish acronym of Costa Rican Association of Alzheimer's and Other Associated Dementias (Asociación Costarricense de Alzheimer y Otras Demencias Asociadas). The main aim of ASCADA was to diagnose. The president of the association was a neurologist with a focused interest in incidence of dementia and prescription of anticholinesterases. How the association was structured and

operated was unclear, as were the number of families that were members. It offered occasional seminars, and an annual national conference. The association created a sub-group The Caregiver's House, Casa del Cuidador, with 100 members, with the objective to help caregivers self-care. Caregivers would learn about their personal holistic care and how to improve their personal quality of life by facilitating the caring process. The Caregiver's House did not teach about dementia or Alzheimer's. It was completely based on volunteers, and offered workshops once per month. The workshops incorporated practices of introspective activities, exercise, informative sessions, artistic activities, group presentation, and refreshments.

Panama also had an Alzheimer's Association, founded in 1995 by a group of medical doctors. The association was neglected for many years, then in 2017, the board of directors was changed and the association was acknowledged by the Ministry of Health. At the time of my visit, the main representative of the association had the responsibility of developing it to receive formal recognition by Alzheimer's Disease International as a branch. Effectively, it was not operational.

The focus of the five associations, the two not operative confirmed their past focuses, were on diagnosis and prescribing dementia drugs. Post diagnosis services were only offered by Guatemala's association: the much needed, affordable, dementia specific day centre. With the exception of Guatemala, the families that were interviewed were either not aware of the associations or they did receive support or information from them. Their aims were vague and ambiguous. Furthermore, again except for Guatemala, in the other countries, organizations found the associations superfluous and not providing the needed support to families. The rhetoric found on the website of Alzheimer's Disease International, the worldwide federation of Alzheimer's associations, states:

“Alzheimer associations provide information and support and can advise you of any services available in your area, as well as answer any specific questions you may have. Getting in touch with your Alzheimer association is one of the most important steps you can take.”

The dissonance between the rhetoric and practice was evident, specifically in the aims. Finally, a sense of competition in a race to diagnose the most in order to



achieve incidence rates, and to incite use of pharmaceuticals. The competition between medical practitioners in the same country to be recognized and remembered interfered with families' needs for support.

## Families Living with Dementia

I interviewed a total of 11 families (Table 11) who narrated their personal stories of caring for a loved one with dementia and dealing with the services in their countries. In the dementia specific networks and the family networks sections of chapter 7, I will discuss the families and their connections to services further. In this section, I will describe the participating families of each country.

Table 10 Families with dementia by country

	Person with Dementia	Diagnosis	Dementia Prescription	Post Diagnosis Support	Contact via
Guatemala	male	neurologist	yes	Alz Ass	Alz Ass
	male	geriatrician	yes	Alz Ass	Alz Ass
	female	neurologist	yes	Alz Ass	Alz Ass
El Salvador	male	neurologist	yes	very little	friend
	male	neurologist	yes	very little	friend
Honduras	female	neurologist	yes	no	friend
	female	geriatrician	yes	no	home visit
Costa Rica	female	GP	yes	no	friend
	male	neurologist	yes	no	Alz Ass
Panama	female	neurologist	yes	no	Alz Ass
	female	neurologist	yes	no	Alz Ass

In Guatemala, three families with dementia were interviewed. Two were diagnosed with dementia by a neurologist, to whom they were sent by their general practitioner. One man never received any diagnosis from his general practitioner at the military hospital, but was diagnosed by a private geriatrician. All three were prescribed dementia specific medication, which they received at no cost through social security and the military hospital. Each individual discussed with me their frustrations and challenges, and were utterly grateful for the day centre of the Alzheimer's association that not only provided support but also taught them nonpharmacological strategies.

In El Salvador, two couples of which the husbands both were living with dementia participated. One was 65 years old, the other 79. Both were prescribed dementia specific medication with diagnosis, and both families complained that they were given very little post diagnostic support and information about dementia.

In Honduras, a friend introduced one of the families; the great aunt was living with dementia alone in her home with a private caregiver. The other family spoke to me during a home visit, to which I was invited, of the interdisciplinary team from the Centre of Integrated Assistance for Older Adults. This second visit was very brief, but the son and daughter in law explained how they were desperately seeking assistance for his mother who was living with dementia and demonstrating challenging behaviours.

In Costa Rica, the daughter of a woman living with severe dementia, totally dependent, and another daughter with a bed ridden father living with dementia in the severe stages, with a naso-gastric tube, and a PEG (percutaneous endoscopic gastrostomy) tube, shared their stories with me. They both described extreme challenges and lack of information and support.

Lastly, in Panama two men shared their families' stories: one, the husband of a woman living with dementia, the other the son of a woman living with dementia. Both men were anxious to share with me but also enquire about dementia. It felt like they were desperately searching for information, solutions, and management strategies.

In general, the families were desperate for support, nevertheless feared taking a stand.

*“The neurologist never has time, it is always the students that visit mom.”*

*“It is a problem going to the appointments, just going to wait and hope [to see a doctor], there aren't any chairs and we are scared to ask for them for [the hospital staff] may take revenge.”*

The interviews with families were the longest, lasting up to four hours, where the family members finally spoke about their challenges and fatigue. Religion played a large role in how families and health practitioners found every possible option to assist the person being cared for to stay alive. Even in the end stage of life, providing a feeding tube, maintaining a person alive without considering the quality of life. The toll on caregivers was also largely ignored by the systems. I wish I could have helped them all more.

## Care Homes

All five countries offered care homes for older adults (Table 12). Public, non-profit and private care homes were present. The commissions of ageing seemed to be attempting to regulate the care homes in their territories, yet many illegitimate homes persisted. Criteria for care homes to standardize factors such as staff, training, admission, and services, were often either missing or unknown. The differences between the public, non-profit and private were indisputable especially in the appearance and number of residents. The public homes gave the idea of post war structures, falling to pieces and desperately needing repairs. Neglect by governments was pronounced. In most popular areas of the capital cities of El Salvador and Honduras water flowed through the pipes on set days, such as every other day, or even without a schedule, intermittently by surprise. Therefore, plastic barrels were placed under the showers of the military style collective bathrooms to collect the water when it ran. This of course prevented regular routine laundry and bathing. Safety measures, such as keeping piles and piles of extra clothing for men and women, were used by staff to counter the water issues.

In Guatemala, two care homes were interviewed. A private, exclusive care home, deemed to be specific for people living with dementia, owned by partners in the U.S., and a non-profit care home administered by a nurse with the Caregivers Diploma. In the private care home which resembled one of the large U.S. chain residential care facilities, residents were very obviously sedated, propped in front of a large television. During the tour, webcams in each room were indicated as an optimal feature, what families want, to observe staff thus maintaining high quality

care. While the staff boasted a social model of care, the doctor was wearing a white lab coat. Based on basic dementia specific criteria such as lighting, contrast of colours, signposting areas and rooms, certain features for private toilets within the suites, and an unsafe, ungated garden, this care home was not suited for people living with dementia. This home's lowest monthly rate was 2500 U.S. dollars, approximately 2000 GBP.

Table 11 Care homes by country and type

Type	Characteristics	Guatemala	El Salvador	Honduras	Costa Rica	Panama
<b>Nonprofit</b>	<i>Cost GBP/month</i>	£54.00	sliding scale/free			
	<i>Capacity</i>	25	100			
	<i>Nursing care</i>	no	palliative			
	<i>Dementia</i>	yes	yes			
	<i>Physical structure</i>	rented	well kept			
<b>Public</b>	<i>Cost GBP/month</i>		free	free		
	<i>Capacity</i>		225	60		
	<i>Nursing care</i>		yes	yes		
	<i>Dementia</i>		yes	no		
	<i>Physical structure</i>		old, need repairs	old, need repairs		
<b>Private</b>	<i>Cost GBP/month</i>	£2,000.00	?			£660.00
	<i>Capacity</i>	43	19			9
	<i>Nursing care</i>	yes	yes/palliative			no
	<i>Dementia</i>	yes	yes			yes
	<i>Physical structure</i>	new	well kept			rented/well kept

Their aim was to attract expats who would spend much less in Guatemala than any private care home in a developed country. Their capacity was 43 residents, and at the time of my visit, 13 older adults lived there.

I did not directly visit the non-profit care home, because it was in a very unsafe area of the city, yet I interviewed the director in person at another premise. This home's operations were based on donations and any monthly contributions from families they received. It was a family run care home in a rented house, with the hopes of either buying or receiving a house in donation. It housed 25 residents, most with dementia. The non-profit requested from families of residents a maximum of 500 Quetzales, 54 GBP per month, based on a family's socio-economic status, albeit the sum is seldom received.

Three care homes were included in El Salvador's service system, one public, one private, and one non-profit, all of which were interviewed. The public care home offered a home to 225 older adults with specific criteria of 70 years of age and older, totally abandoned and at risk, indigent, and without families. The home consisted of 2 large sleeping dormitories divided by gender, a psychiatric unit of 45-bed capacity, which included people living with dementia, and a geriatric unit of 25 residents on palliative care. An exact number of residents with dementia was unavailable, but the consensus was that the rate was high. Among the various staff members I informally conversed with during my full day visit, there was some disagreement on the quality of care and quality of work life. The grounds were vast with gardens and walking areas, and all residents seated outside lined up against the walls of the various inner courtyards. Despite the evident necessity for renovations, it offered a much needed home and care to many older adults who would presumably not have anywhere else to live.

A very different scenario was the non-profit care home. Where the public care home was large, with an unkempt look, feeling packed with residents and beds and with a subtle accompaniment of crying, or residents talking to themselves, or moaning when I communicated directly with anyone, the non-profit care home was tidy, quiet, and seemed to offer more privacy even in a three bed shared room

With a total capacity for 100 residents, at the time of my visit it housed 75 older adults, the eldest 108 years old. This NGO non-profit was based on donations and sometimes government funds. Only 12 of the residents were paying a monthly fee, albeit some received pensions, which went directly to families, and some non-paying residents owned properties. The entrance criteria for this non-profit home was firstly that the older adult want to live there, at least 65 years old, independent, no NCD, at least 1 person in the family with a job to pay a personalized quota, and a clinical evaluation. The director and administrator explained that these criteria were not set in stone. If an older adult had no means of sustenance, the entrance was free in a shared room. The estimated rate of dementia was 60% of residents were living with mild or moderate dementia and one resident in the severe stages.

The private care home I visited was what in the U.S. is categorized as a skilled nursing facility. It was a care home offering highly skilled nursing care providing palliative care to 19 residents. Although clinical, the care home's ethos was based on a social model of care, person centred, asking and respecting residents' wishes and providing affectionate care. The director shared about her insistence in teaching staff how to be loving and show affection to their patients as they would a family member.

*“The medical profession is not taught to give affection, to see the person, not even early career nurses.”*

Most of the patients were left alone, family members rarely visited, only paying the bills and calling to ask about the conditions.

Honduras' network included 2 organizations of the care home type, 1 public care home, and the association, or network, of care homes, both of which were interviewed. The public care home was literally falling to pieces, with missing tiles on walls and pavement, plaster crumbling off the walls and ceilings, yet also boasting large, open spaces, and a lush, green inner courtyard. Two main large dormitories divided by gender housed 15 women and 31 men, with a total capacity of 60. The admission criteria were 60 years and over, at socio-economic risk, abandoned, and/or abused. All residents were dependent, many bed bound, needing nursing care.

The care homes network of Honduras was unique, not present in the other countries. It consisted of a whatsapp group of all administrators of care homes in the country. It was a collaboration of support by means of sharing donations of all kinds, from food to clothing, sharing employees in times of necessity, and finding emergency accommodations for older adults. It was an effective means of communication amongst the care homes, but tied to the larger country network by only one tie through the administrator of the public care home described above, member of the care home network.

In Costa Rica, only one node nominated having a tie with care homes in general. No care homes were visited in this country.

Finally, in Panama, I visited a private care home administered by a gerontologist. Of the 9 residents living in the small, but cosy, rented house, 1 had a diagnosis of schizophrenia and 3 a dementia diagnosis. All women, the residents aged between 76 and 93 years old. The monthly rate was 800 USD, 660 GBP, and a full time (6 days per week) caregiver cost the home 600 USD, 500 GBP per month.

A commonality in all five countries was the prevalent phenomenon claimed by care homes of adult children dropping their parents off to care homes and disappearing, never returning and leaving false contact details. As all care homes interviewed confirmed, this abandonment left care homes struggling for resources, which was found to be compensated, at least in part, through the inter-organizational exchanges as described in the next chapter.

## Universities

Another organization that offers services to older adults in every country is universities. A degree in geriatrics or gerontology is only available in Guatemala and Costa Rica, yet most geriatricians and gerontologists obtain their degrees from Cuba or Spain. Notwithstanding, Central American countries' educational policies include civil duty hours for students. In general, university students must complete 500 hours of civil duty or social hours in order to graduate. The faculties of psychology, medicine, geriatrics, social work, and physical therapy as well as private nursing schools offer their students the possibility to choose where to complete their hours. In addition, most of these degrees entail a practicum. Many students perform their social and practicum hours providing care to older adults in care homes, day centres and hospitals. Therefore, university students are an essential part of the older adult care systems.

## Ministries with Dedicated Older Adult Services

Different ministries in each network were nominated as administering specific programs for older adults. In all five countries the Ministry of Health were involved in awareness events, trainings, workshops, developing guidelines and inspecting care settings. In Guatemala, the health ministry added a section on dementia/Alzheimer's into their standardized book of norms in mental health 2010 edition and the most recent 2018 edition. The Ministry of Labour offered an older adult program of economic support in both Guatemala and El Salvador. In Costa Rica, the Ministry of Social Support offered direct financial support to public day care centres and care homes. The Ministry of Culture and Sports was involved in programs being offered to older adults in the day centres operated by the municipalities in Guatemala. In addition, the Ministry of Education was involved in supporting student practicums within older adult care settings in El Salvador. Finally, in Panama, the Ministry of Social Development collaborated in supporting the recognition of cases of elder abuse and the professional role of gerontologists.

## Dedicated Older Adult Units in Hospitals

Not every country of those included in this study have an exclusive geriatric hospital. However, most networks include a geriatric wing or unit in at least one hospital in each country, except for Panama. Although Panama does have a geriatric hospital, it was not connected to the organizations interviewed, thus was not included in Panama's network. Hospitals, like care homes, were differentiated by their source of funding. Private and public hospitals were present in all countries, where private hospitals were consistently referred to as clinics. The private hospitals or clinics were comparable to any developed country's hospitals. Very new buildings, or remodelled, private rooms, elegant and modern receptions, and technology such as computers, televisions, and monitors, as well as current medical technology. A stark contrast to the public hospitals, which I was advised not to visit. I wrote detailed field notes of the one I did visit, included in this section, because it was a completely new reality for me. It was impossible to



accept the exceptional difference of care given to people living in the same geopolitical area.

Guatemala's Older Adult Clinic is housed in the public Roosevelt Hospital.

*Fieldnotes February 2018*

This hospital is an old, public hospital. The physical structure both external and internal gives that away. Some cracks in the walls, plaster chipping away. Cement, marble, and wooden benches line the corridors. Pale whites, yellows and browns make it seem tired and forlorn.

Metal bed frames that remind me of wartime movies line the emergency area's corridors and fill the waiting room. In the other departments, the beds line the walls of the two sides of the large rooms with feet all pointing toward the centre. A room may have 8 beds, while the larger hall type areas at the ends of the corridors are predisposed similarly without walls in between housing possibly 32 beds. Privacy does not visit here. There are no curtains between the beds. Everyone sees and can be seen. A smell of cleanliness bluntly contrasts the despondent faces and listless bodies that populate the spaces. All eyes peering at me, tired eyes, hopeful eyes, sad eyes, strong eyes meet my eyes as I smile and greet all of them. The two doctors guide me to another hall and walk through a metal gate door, ceiling to floor, which only fits us one at a time. In this area, some rooms are closed off, but I can see inside through the glass windows. These are communicable disease areas with signs not to enter for risk of contamination.

As we exit through the same gate/door, I ask why there is a gate that can be locked. The doctors tell me the story of August last year when a prisoner was being kept and treated in the hospital because prison hospitals are only equipped to handle a primary level of medical necessity. One day a group of people raided the hospital firing machine guns to help the prisoner escape. They killed seven innocent people, including two children. Because of that incident, security was tightened and metal gates were put on certain corridors, which could potentially house a prisoner.

As I look around me listening to the story, I notice a few bullet holes in the wall and in the elevator. It seems unreal, as if I am on a movie set and they are telling me how the scene will play out. Everyone who passes by, smiles, greeting us cordially, as they busily continue on doing their jobs.

The old, cement structure built in 1944, employed about 2800 people. It offered free medicine and free services in internal medicine, surgery, orthopaedics, traumatology, maternity, gynaecology, paediatrics, ophthalmology and sub-specialties including nuclear medicine, diagnostic imaging and clinic laboratories. Roosevelt Hospital housed the Older Adult Clinic (Clinica de Adulto Mayor). It was founded in 2014 and counted about 3000 patients to date, at least 70 years old. The clinic offered geriatric consultations with psychological support and referrals to specializations within the hospital. The team of one geriatrician and one psychologist shared a tiny office space where they received older adults and their family members. Most families are poor or under the international poverty line. Although they may visit the Clinic, often they cannot afford to follow up or follow through with treatments. A visit to the Clinic or hospital in general entails the cost of the bus to and from, most live outside of the city, and the cost of breakfast, because they leave their houses at 4 or 5am, and lunch, most patients are told to arrive at least half an hour before their appointment and often must wait even up to 6 or 7 hours as delays occur.

The Clinic also offered the Older Adult School twice per month for older adults who could make the journey. Students from the faculty of psychology and occupational therapy of nearby universities completed their practicum hours in this school leading creative activities for cognitive stimulation and occupational therapy. A snack of pan dulce y fresco, the traditional sweet bread and fresh fruit juice, reinforced the socialization between the fluctuating 40-60 participants who told me they had fun, rather than staying home alone they had made friends. Some went with a caregiver, some with a friend, all were well dressed in colourful skirts and shirts and well groomed, some had teeth missing, some were indigenous, and a few were men. They gathered in the basement of the hospital, in a large dining hall in the only space available, and sat in random groups at plastic benched Tables.

In El Salvador, within the private Hospital of Women, exists a private geriatric clinic. The geriatrician founded the clinic 9 years ago. It comprised of a multidisciplinary team of professionals to refer patients to. The team consisted of a neuropsychologist, a nutritionist, occupational and physical therapists, a neurologist, psychologists, social workers and nurses trained in geriatrics. The geriatrician called it a private support network, private referring to the financial aspect.

No hospital or dedicated older adult unit within a hospital was included in the networks of Honduras or Panama. This does not mean that they did not exist, only that the organizations interviewed had no ties to any.

In Costa Rica, the National Hospital of Geriatrics and Gerontology of the national social security, offers care to the population of 60 years and over with multimorbidities, dependency and socio-economic risk. The hospital acts as an academic hospital for the University of Costa Rica's geriatrics specialization With 140 acute beds and 5 domiciliary teams. It was founded in 1958 as a hospital for tuberculosis, until 1976 when the hospital began to focus on older adults. The hospital also founded the first Memory Clinic of the country, based on the biomedical work of Prof. Anthony Bayer in Cardiff on memory assessment, diagnosis of dementia and pharmaceutical prescription. The memory clinic will be described in more detail in the Memory Clinics section below.

## Memory Clinics

As aforementioned, memory clinics were present in El Salvador, Honduras and Costa Rica.

In El Salvador, four Memory Clinics were part of the social security institute (ISSS) although they claimed to offer services to all citizens regardless of their membership. The founder, a neurologist, stated that the name Memory Clinic was used to "avoid stigma" associated with dementia. ISSS covered 1.5 million

members of which 20% older adults, amounting to approximately 200,000 older adults plus their spouses according to the founding neurologist.

In January 2006, the first memory clinic opened to people with dementia and their caregivers. During my visit, I met with the entire team of professionals, all in white laboratory coats. They described support as diagnosis and prescriptions of memantine and donepezil, covered by the social security institute, and non-pharmacological therapies. The families that I interviewed did not attest to this, but claimed the clinic offered only talks and presentations. Post diagnostic support was not a focus. A national internal plan of the ISSS “Integrated Management of Memory Disorders” was in place from 2015. Clinics followed a strategy based in neurology and psychiatry. Courses for caregivers were also offered, where caregivers were evaluated for depression using the Hamilton scale of depression (HRSD). Seminars on self-care and integral care were given once per week for 12-week sessions. The families I interviewed reported that they found it very difficult to attend seminars, as they did not have caregivers for their loved ones living with dementia.

*“The talks were not very informative - [she] said that my presentation gave her much more information to help her understand and help her husband and herself.” (Family interviewed)*

According to the clinic, following a diagnosis, the clinic provided a specific course for the type of dementia diagnosed then meetings about different therapies and groups for the specific causes of dementia. Additionally, twice per month the person with dementia was given appointments for cognitive stimulation, reading books and debate, for those capable, occupational and physical therapy, and relaxation.

In a hospital in Honduras, a group of neurologists founded the Memory Clinic for older adults with dementia. Once they diagnose an individual by means of a one-hour evaluation consisting of a battery of tests, the person is referred to the clinic. Once per month, groups of maximum four persons living with dementia meet for cognitive stimulation. At the time of my visit, the clinic had 32 members with

dementia. The clinic also provided donations of 6-month doses of the commonly prescribed anticholinesterase drug donepezil. This Memory Clinic was the only in the country, but was at risk of closing if the acting director retired, as no new contracts were being offered. Neither the clinic nor the hospital's psychiatry department could provide statistics on the number of hospital patients diagnosed with dementia.

Costa Rica proposed a disconcerting scenario. Two memory clinic formats, non-collaborative, founded by two different doctors in different hospitals. The director of one hospital claimed that the first memory clinic was founded in the geriatric hospital and was later replicated with a severely clinical focus and as a variant in another hospital. The first memory clinic was founded based on the person centred approach of care, with the aim to support families by providing education and nonpharmacological strategies. Competition and resentment between the contrasting approaches of the clinics and the practitioners were easily palpable. The memory clinic for which I collected details was the first of ten, founded in 2010 by a neurologist, coincidentally the president of the Alzheimer's association, with the aim of research and support. The clinic received approximately 500 patients per year, offering them a multidisciplinary team of geriatricians, neurologists, psychiatrists, medical doctors, clinical psychologists, social workers, nurses and gerontologists. Individuals passed through the five phases of the clinic:

1. Medical screenings;
2. Memory evaluations;
3. Team consensus of diagnosis;
4. Post diagnostic support;
5. Prescription drugs and 3-month revisions

According to the director of the clinic, using prescription anticholinesterase drugs lowered care costs because they allegedly (Fox et al. 2013) decelerate cognitive impairment.

It was clear that the ambition of the founders of most of the memory clinics was to be the pioneers in finding national prevalence rates of dementia. This was reflected in the lack of support and services offered post-diagnosis, communicated

by the families, as well as the findings portraying low referrals from the memory clinics to other service providers, detailed in chapter 7.

## Gerontology or Geriatrics Associations

Although not every country had gerontology or geriatrics degrees offered, professional associations of these studies were present in four of five countries' networks. Although Costa Rica's association was a centre for older adults rather than an association of gerontologists. Nevertheless, they give value to gerontology as a field, and consequently to the degrees conferred. All of the associations were non-profits.

Guatemala's gerontology association was not very active during my visit. Analogously, in El Salvador an Association of Geriatrics existed, but was seemingly inactive at the time. In Honduras, neither a gerontology association nor a geriatrics association existed.

Costa Rica's Gerontologic Association was AGECO, acronym for the Spanish name Asociación Gerontológica de Costa Rica. The mission of this association was to promote active ageing since 1980. Founded by medical doctors, 6 gerontologists are employed. AGECO offered leisure, artistic, and sports activities with a swimming pool, as well as social and cultural events. Members could participate throughout the national territory by enrolling in one of the 105 subgroups known as clubs. Another subgroup of the association, the Gerontological Institute of Training, founded in 2012, offers continuing educational courses on site and online for members. Membership criteria was 50 years old and above, and independent. Dementia was a topic not included in any materials or courses. In contrast to the other country's gerontology associations, this one was founded as an association for older adults, rather than as a professional association of people with higher education degrees in gerontology.

In Panama, the Gerontology Association, AGEPA, acronym for the Spanish name Asociación Gerontológica de Panamá, is protected by a legislation of 2009

recognizing gerontologists as professionals. More than 300 gerontologists are present in Panama where the public university offers a four year gerontology degree, 80 were members of AGEPA. Nevertheless, there are no places in the job market for gerontologists because the government does not regulate the role in care or other ageing settings. The main objective for AGEPA at the time of the interview was to create places of employment for gerontologists, via political lobbying.

## Municipalities

How the municipalities were organized, funded, and how they operated was beyond the scope of this study. Those that emerged in the networks had specific older adult departments that, with the exception of one in Costa Rica, were impossible to interview.

Only in Costa Rica was an interview conducted with employees of a municipality. In three other countries interviewees nominated having ties with municipalities that cooperated in supporting older adult services, as described below.

In Guatemala, the municipality of the capital city had a secretariat for older adults. This secretariat collaborated by way of offering their employees to train with the Alzheimer's association. The municipality also offered scholarships for the caregiver's diploma. Jointly with the commission for persons with disabilities, the municipality advised in developing and regulating social policies. Additionally, a representative of the municipalities had a designated seat in the commission on ageing. Lastly, the municipality partnered with the older adult clinic in organising programs and events by offering logistical support.

In El Salvador, the municipalities belong to a consortium, which has a designated seat in the commission on ageing. The municipality of the capital city collaborates with the Alzheimer's association and the military retirees association by way of providing transportation, and supporting logistics for events such as public spaces and permits.

In Honduras, the University of Honduras nominated having an informal agreement with the municipality of the capital city. Students could complete their social civic hours or practicum in the municipality and the municipality offered material resources such as supplies.

A written agreement tied Costa Rica's Alzheimer's association with the municipality of the capital city. The collaboration consisted in promotion and divulgation of information, joint public policy creation, and joint development of public screenings for Alzheimer's. In addition, municipalities supported older adult awareness and services by cooperating in organizing conferences and workshops, and providing spaces for events.

Although in Panama's system, municipalities were not nominated, the cooperation of municipalities within the systems proved to be an important asset for all. At the community level, by allowing spaces for older adult and ageing themed events, municipalities promote raising awareness.

## Human Rights Commissions

Every country had a commission of human rights acting as public ombudsmen. Three of these commissions had specific older adult departments dedicated to advocacy for the rights of this specific group. These dedicated departments are even more relevant and significant because they operate in territories with no apparent policies delineating physical, emotional, psychological, or financial abuse and mistreatment of older adults. The basic protocol, derived from the interviews, is to call the police if abuse is suspected. This applies to staff working in care settings as well as families.

Guatemala's Human Rights Attorney's office offered a dedicated department to older adults. The department, run by one person, provided a weekly support group for older adults, inclusive of activities and snacks, and performs supervision of public institutions.



The Human Rights Defence Attorney in El Salvador also offered a dedicated department for older adults. It consisted of a psychologist, with a psychology undergraduate degree and a master's in gerontology, and a lawyer. This office developed an Older Adult Roundtable in 2012, of 32 associations to promote the rights and empowerment of older adults to know the laws and awareness of good treatment. They aimed to protect individuals or authorities. They provided abandoned elders with no identity temporary decrees.

Panama's Defence of the People was also an autonomous institute of the nation that advocates for human rights by theme or group. One of the defenders was dedicated to the department of older adults. The role of this office was to promote awareness of the rights of older adults for example to employees of public transportation, and manage complaints.

### Commission on People with Disabilities

Three countries had a Commission for Persons with Disabilities as part of the older adult services network. All three were interviewed, although data was not collected from Panama. Because the office of the secretariat, which held the specific function of assessing and registering people for type of disability, reported that they were not in contact with any explicit older adult service providers. Yet, the idea of creating a department focused on older adults was deemed appropriate and constructive.

In Guatemala, the Association for Persons with Disabilities, dementia was not considered a disability in itself, rather a cause of disabilities. They did not have a specific department dedicated to older adults. Their main duties were to coordinate policies advocating for persons with disabilities and guarantee that the government respected them and took responsibility.

In El Salvador, the Commission held the duty of controlling and regulating the rights of persons with disabilities. The actions included empowering families, managing complaints, and coordinating support. The commission did not provide

any direct services to families, but indirectly they did through training professionals in the older adult sector on disability rights. The main aims were to help people become conscious of and to respect all phases of life, and to raise awareness of the laws in existence protecting the rights of all. The commission was also dedicated to changing the focus of disability from the medical model to the social model.

In Panama, the National Secretariat for Disability (SENADIS, the Spanish acronym), was founded in 2007. It is directed by the National Consulting Council on Disability (CONADIS, the Spanish acronym) which promotes SENADIS' compliance with specific objectives. The main functions of SENADIS are the certification and inspection of disability. In total, four thousand people had been evaluated and 3,500 certified disabled. Using the World Health Organization's International Classification of Functioning, Disability and Health, people are assessed for levels of disability and need of durable medical equipment. The evaluation is determined by at least 3 people per case through a biopsychosocial approach. With regards to dementia, capacity must be determined legally, but with a dementia diagnosis, a person may be assessed for disabilities.

The presence of these commissions on disability raised acknowledgement, awareness and sensibility of disability and inequality, fundamentally advocating for the rights of persons with disability. Although none of the commissions had a specific older adults department, each allowed dementia to be taken into consideration in the theme of disability. Notwithstanding, in the northern countries, the high rate of disability from the recent civil wars and from gang violence placed older adults and dementia on a long waiting list for possible support.

## Day Centres

Guatemala, El Salvador and Costa Rica offered day centres for older adults.

Guatemala boasted a state run program stemming from the Secretariat of Operas by the First Lady (SOSEP), to provide social support by way of day centres

entitled *Mis Años Dorados* (My Golden Years). Two psychologists managed the program. Seventy-five day centres present in 56 municipalities of the total 333 municipalities in the country. Alliances with other state institutions such as universities, some permanent others temporary depending on personal relationships, permitted students to complete their social service hours or practicums.

The day centres were initiated in 2012. The criteria for participation is 60 year old and above, in possession of a national identification card on the date of joining, a photo to create a personal record, and acceptance to be visited at home, and functionally independent. The centres run from 8am-5pm Monday through Friday, offering a snack at 10am, lunch and an afternoon snack. Some participants receive breakfast or bring their own to eat at the centre. Each centre had an agreement with each municipality to provide medical attention and transportation for older adults. Activities of cognitive stimulation were said to be offered by students of the faculty of psychology of the state university, physical and occupational therapy degree students and students working toward the caregiver diploma completed their practicum hours in day centres. In addition, medical days for testing hearing, vision and blood were held in the centres and all participants received free evaluations.

The seven fundamental axes of the centres were established as health, physical and occupational therapy, socialization, culture, ludic, recreation, and education. Fifty participants was the ideal maximum capacity for each centre. SOSEP covered 80% of costs and required municipalities to cover the remaining 20%. Each centre presented 6 staff members: 1 administrator, 1 secretary accountant, 1 auxiliary nurse, 1 occupational therapist, 1 cook, 1 auxiliary cook, and volunteers. SOSEP guidelines state that each centre should be monitored twice per month. I attempted to visit a centre in the vicinity of the main SOSEP office, but I was disappointed to find a sign that they had gone on a fieldtrip.

The Institute of Social Security (ISSS) of El Salvador offered seven Day Centres of Attention for Older Adults in the national territory for independent persons. Membership criteria were at least 66 years old for males, and 55 years old for

females, an initial evaluation to determine physical and cognitive health, no NCD, and be insured by ISSS. If a person had a physical disability, they needed to be accompanied by a private caregiver. Participation was free to activities and classes.

In Costa Rica, one private day centre was part of the network. Located on a hill in a town just outside of the capital San Jose, Casa Sol hosted older adults with dementia Monday through Friday from 9:30 to 15:30. The house was large, well lit, with open spaces and was surrounded by beautiful gardens, plants and flowers everywhere and an exquisite view of lush, green hills. It was very serene. Founded in 1995 by a psychologist with a Masters in Gerontology, a psycho-gerontologist, Casa del Sol was a private day centre with approximately 40 members. Daily the centre served about 23 older adults offering physical therapy, group psychotherapy, individual psychotherapy, exercise, art, yoga, gardening, vegetable garden, singing, history, dancing, internet navigation, lunch and two snacks, and cognitive stimulation. The centre boasted its own equipped physical therapy zone in the garden area and multi-functional, trained staff included: 3 psychologists (one the psycho-gerontologist), 1 physical therapist, 1 general medical doctor, and 4 resident assistants. Family clinic sessions explained to family members how to manage, care for, and support their older adults with dementia. For those who wanted to take advantage, individual psychotherapy was also offered to family members to assist in coping with changes and challenges. The daily cost was 34,000 Colones, (45 GBP) but monthly memberships were discounted and included transportation to and from home with a trained driver. Participant criteria only excluded verbal or physical hostile behaviour. Persons who needed toileting assistance were required to be accompanied by their own private caregiver.

Although the majority of the day centres did not allow persons with dependencies to participate, the structure and unique use of scarce resources, which will be expanded on in the next chapter, such as student social hours, could be imported to other countries.

## Older Adult Integrated Care Centres

Two countries offered integrated health centres exclusively for older adults. Both Guatemala and Honduras, through the social security systems. Honduras' integrated care centre was the first and only of its kind in my experience. Based on the concept of providing integrated care from a public health perspective, it puts into practice an ideal. Unfortunately, not only the lack of funding, as described below, impedes Dr Pineda's utopian vision from succeeding.

Guatemala's CAMIPs, acronym from the Spanish Integrated Medical Centres for Retirees, offer health and social attention to retired employees and their dependents. The first CAMIP was founded in 1985 with the third opening in 2011. According to a former employee, the majority of patients were men and widows. Of the 22% of the population covered by social security benefits, 4% were CAMIP members. These centres acted as medical day centres, providing free visits and medicines. The social security offices and employees I attempted to contact repeatedly did not reply to my interview and visit requests.

Honduras offered a unique and effective paradigm, albeit in desperate need of funding. The Centre of Specialized Integrated Care for Older Adults (CEAIAM the Spanish acronym) is Honduras' social security's (IHSS) response to providing multidisciplinary care to the older adult population. It was founded by geriatrician and gerontologist Dr Angel Pineda. The centre provided consultations, had an internal pharmacy, and offered home visits to those who could not make it to the centre. The CEAIAM team consisted of 9 medical doctors, 1 with a newly earned Masters in Gerontology, 1 psychologist, 2 social workers and 2 gericulturists (how older adult activities specialists are referred to). About 4,000 older adults passed through the centre on a monthly basis. Each adult that is a member of social security is automatically passed on to the CEAIAM when they are 60 years old, as per Honduran law 60 years of age delineates an older adult.

### *Fieldnotes May 2018*

A strain on the system and the older adults is the first come first serve policy. Appointments are not used here. As was explained to me by a

woman waiting, she woke up at 4am to arrive at the centre by 5:30am and stand in line until the centre opened and gave numbers. Although she came at dawn, she was visited while I was still there, at 12pm. The protocol is that each older adult must pass a doctor's visit every 3 months in order to renew their prescriptions. Once per month, each older adult must go to the centre's pharmacy to pick up their medicines, which are given free. A big problem is that often the pharmacy does not have medicines. If a family has money, they may buy the medicines in another pharmacy. Otherwise, they must come back the next day, or the next week to stand in line to ask if their medicine has arrived. The director has put in effort to make the environment less grim. Yet the paint is old, white, grey, with few decorations, and poor signage if any. I myself got lost. The vibrant and passionate team of social workers, psychologist and geriatricians provide a cognitive stimulation calendar, and a rich social activities calendar. The Honduran Social Security Institute (IHSS) has opened one CEAIAM subsidiary in the other main city, San Pedro Sula. I hope that some investment into the infrastructure and medicines of the first CEAIAM will also be part of the plan.

## Summary of Services

The above descriptions portray health and social care services for older adults in the Central American region as based in the biomedical approach. Diagnosis is a priority even in developing countries where prescriptions are the first response to a dementia diagnosis. It can be deduced that more government funds are put into diagnosis and prescription drugs than to awareness, care and support, education and training.

Nevertheless, what stands out in the region are the parallels across countries is the structure of the service systems for older adults. In response to doubts on how Latin American, countries can implement models of care (Parra et al. 2018); Central American systems present a co-designed framework with a commission, which involves various partners. Two countries, Guatemala and El Salvador had

thirteen of the same organizations in their networks, while Costa Rica had 11, Honduras 10, and Panama 9 of the same organizations as the other countries. These parallels demonstrate a common basic structure with main sustaining columns, such as the ministries, commissions for human rights and disabilities, universities, care homes, Alzheimer's associations and dedicated older adult health care units. Other organizations can join the structure, such as private and non-profit entities, and influence the directions it takes. However, the overall strength of the structure is that it exists in a community, where on a regional level the structures can be compared to learn from each other. This is a form of integration at a higher macro level of regional standards.

In the next section, the older adult service systems are explored through a national perspective. Where integration standards take into account context, thus conform to the needs of the individual countries.

## National Perspectives

This section delves into the uniqueness of each country, and specific context is provided from fieldwork to affirm it. Though the founding structures were in place, the reality of collaboration was different in each country, as will be described. Although daily life in the capital cities (except in Panama) and the surrounding areas was precarious, the will and passion of many allowed services to exist. Every country had at least one service particular to that country.

### The Outliers and their Contexts

The conspicuous differences between the country systems were in the outliers, organizations present exclusively in one country's network, not present in any other's. These organizations were of salient value to the older adult populations. These outliers are described in this section, together with details contextualizing the systems illustrated in this chapter, and a final reflection focuses on the perspective of dementia related services.

Guatemala's is the only network to include a Department of Regulation, Control, and Accreditation of Health Facilities (DRACES, acronym from the Spanish name). In terms of regulation, this institute was the only one of its kind in the five countries. DRACES had a department dedicated to older adults consisting of 38 inspectors and supervisors who aimed to be flexible in improving care homes by educating and assisting administrators to abide by regulations rather than shutting them. Each inspector was required to have at least a university degree in a health field. Inspections of care facilities were mandated to occur within the first year of opening, then once every two years. Another outlier present in Guatemala's network was the Central American Integration System (SICA, acronym from the Spanish title). The objective of SICA is "to integrate Central America to constitute a region of peace, liberty, democracy and development" (SICA 2019). The only organization to nominate having a tie to SICA was Guatemala's National Council for Persons with Disability.

The network of Guatemala was also the only to include an international organization, the Pan-American Health Organization (PAHO). Ties to the PAHO were nominated by five organizations: the Alzheimer's association; Galileo University; the Older Adult Program; the Council of Persons with Disability; and the Secretariat of Operas by the First Lady. All five nominators claimed PAHO provided them technical support, resources and training.

Guatemala proved to have the largest system of older adult services in the region, perhaps correlated to being the largest country of the region. Practitioners in one organization were often on the boards of other organizations, which at first glance appeared to create conflict of interest, but subsequently this created links between organizations, which fostered collaboration. From the interviews, the awareness and knowledge the organizations had of each other and the services they provided was clear, unlike in the other countries. The interviewees proclaimed their desire to cooperate, to strengthen services, to be able to do more. Lack of funds, and safety and security issues were the highest concerns for even being able to serve older adults. The capital was unsafe. It was unsafe to walk anywhere because of the risk of assault with a weapon. The options of public transit also are high risk for assault and robbery. The safest means of travel were taxi. The few people walking, or the few areas safe enough to walk, people had nothing in their hands,



sometimes backpacks. Each city had its “safe areas” near important embassies or gated communities. Guards with pump rifles were literally everywhere, in front of shops, malls, banks, restaurants. Living there left me feeling trapped, which very likely was ingrained in people, living in constant stress mode. This underlying absence of safety and security, a physical and psychological basic need, surely had an impact on trust, which is directly related to cooperation and collaboration. The participants were very attuned to the state of risk and issues of trust in their countries, manifested during the interviews when discussing how services could not be provided in certain areas of the cities, or to pockets of the older adult populations due to extreme violence.

El Salvador’s network also presented three outlying government organizations. One was public dormitories, not exclusive to older adults but inclusive of them, administered by municipalities. The other was the Centre for Integrated Services for Armed Forces Retirees (CAIPSFA, acronym from the Spanish title), administered for and by the nation’s military. CAIPSFA offered a day centre only open to independent older adults, Monday through Friday. It was currently managed by two social workers, one physical therapist, and one odontologist; although in the past, it included a geriatric unit with doctors, a psychologist and a nutritionist.. All participants could only be referred to the military hospital. They occupied a space within a military offices building with a large inner courtyard where they offered classes (English/computer), religious events, educational workshops, and recreation such as traditional dance classes. Military retirees or their spouses needed to become members to participate. At the time of my visit, they boasted 100 permanent members participating weekly.

The third outlier in El Salvador was an organization known by its acronym FUSATE, The Salvadoran Foundation for the Third Age. Founded in 1990 as a nongovernmental organization, FUSATE was renowned nationally for providing support and care to older adults living in poverty, abandoned, and/or homeless. The foundation operated by the graces of teams of volunteers who managed the 8 day centres, 2 dormitories, and the central branch that provided food baskets (beans, flour, coffee, sugar, rice, soap) to registered needy elders. The foundation

received no funding, and survived on donations. Health, nutrition, recreation, occupational therapy, intergenerationality, and socialization were what FUSATE aimed to contribute. One dormitory closed its doors at 8pm for safety. It provided 100 beds and 3 meals per day. The other dormitory gave 40 beds and 3 meals per day. All users were registered through an initial evaluation of physical and mental health. The criteria for membership was to be independent and not present with any non-communicable disease.

*“Public care homes is waiting for death, everyone is treated equally here. We provide a place of dignity.” (Fusate staff member)*

The day centres received an average of 60 participants. Membership was given to individuals with national identification cards. If an individual was not in possession of an identity card, a common occurrence in a country of recent civil war displacing so many and with high rates of poverty, the law allowed age to be based on physical characteristics. Political emblems were not permitted in any of the centres or dormitories. Every day centre developed individual local networks encompassing taxis giving discounts to older adults, older adult volunteers, and students completing social hours for their university degrees. Activities, lunch and snacks were included in the day at no cost. The only stipended staff of each day centre were one administrator, one cook, and one cleaner. The day centres received a minimum 40 to a maximum of 150 participants per day.

The smallest country in the region, El Salvador was also burdened with very high violence and poverty. With the exception of a few beach towns frequented by foreign surfers, walking around was inconceivable. The rate of femicide was the highest in the world. The rates of assault were also very high. Analogously to Guatemala, public transit was high risk so the main mode of transport was taxis. Racism was widespread. The colour of one's skin made a difference. Brown people were suspicious, in guarded communities darker skin people, usually indigenous, were stopped and questioned. Most brown people worked for the higher class that were usually mixed race with European descendants. The higher class all had house cleaners, housekeepers, gardeners, cooks, and private guards. The workers spent hours on buses taking them from their villages outside

of the cities into the city to work and back. Some up to 3 hours one-way! One housekeeper of a friend lived without electricity in her home. Again, the safety and security issues affected services for older adults. Care workers could travel only by daylight to lower the risk of assault, so night shifts were 14 hours long. Many villages were territories of drug cartels. Any care worker needed the permission of the cartel to enter and exit the villages. A health worker drawing blood samples from patients in one of these villages was killed because she had asked too many questions about the cartel. Consequently, many families remain isolated if they cannot reach the centres. Within these scenarios, the people I interviewed fight to maintain and grow services. The founding structure of the system and the outliers present in El Salvador are evidence that where there is a will there is a way.

In Honduras, the two outliers were pensioners' associations. The Federation of Associations For Retirees of Honduras (FENAJUPENH, acronym from the Spanish title), is an agglomerate of twelve pensioners associations which includes the Military Pensioners Institute, the Social Security Pensioners Association, and the Higher Education Pensioners Association. FENAJUPENH was nominated by the Commission on Ageing. The National Association of Government Pensioners (INJUPEMP, acronym from the Spanish title), is also included in the abovementioned federation, but was also nominated separately as connected to the Centre of Specialized Integrated Care for Older Adults.

Honduras was another very dangerous, violent country, where safety and security were not a reality. Taxis were the safest mode of transportation, although also prone to assault. Like in the previous two countries, faucet water was not drinkable; it was contaminated with amoebas and parasites. Garbage was everywhere, produced by the heavy use of plastics to take out food, and plastic bottles for everything. The sewage systems were also precarious, where toilet paper could not be thrown in toilets, only in garbage bins, and areas surrounding the capital cities with open sewage water streams. The sidewalks were not maintained, thus were extremely difficult to use, deleterious for older adults with any mobility issues. These factors together with high poverty rates, contributed to the increase in vulnerability of older adults to disease, and to the complications of

receiving care and support. The political settings in all of the countries also had a ripple effect onto the provision of older adult services.

*Fieldnotes: June 7, 2018*

Here in Honduras it is a bit of a mess. The political status really changed a lot and associations do not function and people are against each other and do not want to work together. A lot of personal friction.

Political parties and politicians decide which programs exist, which do not. They decide where to place funding. However, the lesson Honduras teaches is that political parties also divide the people. Even where the common aim of assisting older adults is clear, the ramifications of political views can sever cooperation.

Costa Rica was the only country to have an entire hospital specifically dedicated to the older adult population in its network. Therefore, although it is included in the Dedicated Older Adult Units in Hospitals subsection, it is also an outlier. Following on the theme from Honduras, services based on personal levels emerged as a key element in Costa Rica. The difference in economic power between the northern countries and the southern countries of the region led to unexpected findings. In a country of much higher safety and security during daylight than those aforementioned, and with a high presence of tourism and foreign residency, cooperation was scarcer as will be highlighted in the next chapters. Though the structure of the system was in place, people shunned away from offering information about their services or how the system operates.

In Panama's network, one outlier also emerged. The Intergenerational Group, led by an ex-legislator and founder of the University of the Third Age, was nominated by a private enterprise. The Group united members of the University of the Third Age, the Gerontology Association, members of the faculty of Gerontology, and other associations, with students from various schools and universities, to build communication and understanding of the value of older adults for society. Panama was the safest country in the region, yet with a high rate of poverty and violent areas. Also, the most chaotic in service provision. Few of the members of the network knew each other, rarely even aware of many of the providers. The

enthusiasm for collaboration and sharing was undoubtedly the highest in Panama. Albeit the work setting of disorganization and confusion made for an uphill climb toward integration. For example, the basic structure beginning with a commission on ageing was a giant step for the government in acknowledging the need. Yet only a handful of organizations were aware of the commission's existence.

## Conclusion

In countries where poverty, violence and narcotraffic were on the forefront every day, as described in chapter 4, older adults were deemed a priority in the Central American region, by the people working in the field. Those involved in the field of ageing and health and social care services were all very passionate about doing as much as possible, but also cognizant of feasible expectations, with slow progress and low hope. Living in corrupt and violent areas such as the Central American region demands an adaptive spirit to be accepting of the small achievements, without requesting too much, which could risk entire programs.

Acknowledgment of the dearth of services in every country was high. Families confirmed the lack of support and information, and the isolation, where they seldom had any knowledge of dementia specific services. The general regional atmosphere surrounding dementia could not help but be a contradiction. On the one hand the knowledge of the very real priorities of extreme poverty and violence, where funding is attributed, and on the other the same knowledge of the looming shift in demography and the consequential rise in dementia thus in healthcare costs, where funding is not ascribed. From an external observation, the dilemma of which vulnerable population to provide funding to, or which sector to prioritize, health or social development, is an impossible one. Yet the findings of this study show that funding may not be the only solution, nor the necessity for providing support to families with dementia. In the next chapter, the exploration of the interactions between the organizations will portray a quid pro quo system of exchange that currently sustains the older adult service systems described above.

# Chapter 6: Connecting

## Introduction

This chapter presents the findings of the connections between older adult and dementia service provider organizations. Before delving into the characteristics of the inter-organizational ties, the findings from the analysis of the types of organizations, or nodes, (the terms will be used interchangeably), will be outlined. This analysis allowed for the categorization and anonymization of the organizations that facilitated the additional analyses described in this and the next chapters. The findings from the SNA analysis and discussion on them will be presented in the next chapter.

Next, the findings of the attributes of the ties between organizations are described. These attributes are organized into six main categories and will be described in detail below. The chapter is divided into three main sections. The first describes the findings of the types of nodes, and the second section is dedicated to the types of ties and to cross analyses between types of ties. The final section focuses on dementia specific nodes and ties.

As outlined in the methods section, the data I collected was sorted into six distinct parts, each an attribute of the nodes or ties: types of nodes that are in the networks, types of ties that exist between the organizations, reciprocal ties where both nodes nominate having a tie with each other, the strength of the ties between the nodes, what is exchanged among the nodes, and dementia specific ties. A sub-attribute also emerged: multiplex ties within the exchange category, consisting of organizations that reported ties with more than one type of exchange, named a multiplex exchange tie. The findings of these node and tie attributes will be discussed in the following sections.

## The Nodes

As discussed in the methods chapter, sampling was completed using snowball and reputational methods beginning with the Alzheimer's association in each country. Every individual organisation interviewed was asked to list the other organizations relative to older adult services, they had a tie with. These lists were the personal networks of each organization. All of the lists of one country, united, became the larger vision of each country's older adult services network.

The total number of organizations interviewed and from which data was collected, are shown in Table 1. The 8 organizations from which data was not collected were 1 in Guatemala, 4 in Honduras and 3 in Panama. Why data was not collected from these interviews is explained in the subsequent paragraphs.

In Guatemala, I interviewed the department of mental health, within the ministry of health. Although I obtained information regarding how the health system is organized and that dementia was added to the national book of mental health conditions, the department did not have any ties with any organizations supporting older adults.

In Honduras, four interviews were completed without collecting data for the structured questions. These were with representatives of the Alzheimer's association, the care home network, the Institute for Social Security of the Autonomous University of Honduras' Employees (INPREUNAH, acronym from the Spanish title), and the late geriatrician Dr Pineda. The prepared questions of the interview guide were not answered for differing and unique reasons. In the descriptions below, these reasons become apparent for the Alzheimer's association and the care home network. With regards to the interview with the representative of INPREUNAH, data was not collected chiefly due to time restraints.

In Panama, interviews with the Alzheimer's association, the National Secretariat for Disability, and the Intergenerational Group, did provide data. The Alzheimer's association's situation is described below. The Secretariat for Disability did not have any connections to older adult service providers. The Intergenerational

Group was formidable, my first contact in Panama, growing my contacts in the country through snowball and reputational methods. Unfortunately, due to time restrictions an interview was not completed. Nevertheless, from my three visits, I was able to assess the fragmentation of the system, and the group's disconnect to service providers.

Table 13 shows the quantity of nodes in the systems by country. The number of nodes interviewed and from which data was collected are different

The explanation of the number of interviews were firstly directly related to the sampling methods, how many organizations were nominated.

Table 12 Number of organizations in networks

	GUATEMALA	EL SALVADOR	HONDURAS	COSTA RICA	PANAMA	TOTAL: 5 Countries
n. of interviews	17	16	14	10	11	68
n. of network interviews	16	16	11	10	8	61
n. of orgs nominated	37	26	17	23	10	113
n. of orgs in network	53	42	28	33	18	174

Secondly, contact was attempted with the nominated organizations to schedule interviews, via any given contact person, or contact details found through research of the internet, or asking previously made contacts. The last row in Table 1 shows the total sum of nodes from which data was collected and the total number of nominated nodes. The categorization or grouping of the organizations will be described, by type of node.

### Type of Node

This study is based on the connections among providers of services for older adults and more specifically older adults with dementia and their families. These



providers are various types of organizations. These organizations, or nodes, that provide services include families who provide support to their loved ones living with dementia. Families were taken into account as social organizations in this study, as explained in the Methodology chapter. Eight types of nodes emerged as present in all five countries' networks (Table 14).

Table 13 Types of nodes

AH	Care Homes
F	Families
G	Government
H	Hospital
N	Non-profit
P	Private
S	Security
U	University

Alzheimer's associations were grouped into the non-profits type of organization in most analyses to maintain anonymity, except in reciprocity and in the exchange attribute. Due to the associations' highly specific dedication to families with dementia, and the starting point of research in each country, understanding if their connections were reciprocated and what was exchanged between the other types of organizations and the Alzheimer's associations was considered fundamental to the impact of this study. The exchange data may represent the needs of an association providing dementia specific support in developing countries. In this chapter, the Alzheimer's association will be described individually to allow for cross-country comparison.

Categorizing the organizations into types showed what types of organizations provided services to older adults and their families in each country. Grouping organizations into types also maintained anonymity to subsequently present subjective tie strength scores. Additionally, a review of the quantity of each type of organization within each network can offer insight into the possible skewing of a network and the potential consequential availability of services. For example, if a network is made up of a majority of private organizations, this could mean that many services are provided on a payment basis; therefore those older adults that

cannot afford to pay are excluded from receiving services. Similarly with the opposite effect, if the majority of organizations are non-profit and they prioritize older adults that do not have an income for example, older adults that do receive an income are excluded from receiving services from these organizations. Alternatively, if the majority of the nodes of the network are governmental, this could constitute effects of authorization or forced partnerships on other organizations. In sum, the type of organization is an important attribute of the actors in a network as it has potential effects on the provision of services as well as the other actors.

The original network boundaries, or inclusion criteria for each type of organization, were established chiefly as organizations providing services to and for older adults. To maintain that criteria as a theme in analysis, the services provided initially dictated the type of organization, for example, a private hospital was considered a hospital rather than a private enterprise, a care home was a care home notwithstanding who it was funded and operated by. As a secondary criteria, where primary criteria did not apply, group affiliation was used, for example a centre of integrated care for older adults established by the social security system, was in the social security type, and a private day centre was allocated to the private type. The government category included any services directed or operated by agencies or departments based in the government such as ministries, municipalities, and regulatory associations. Table 15 outlines the organizations in each country's network and the type they are categorized as. The eight types of nodes are care homes, families, government, hospitals, non-profits, private, social security, and universities. A more detailed description of the criteria for each type follows.

The care homes type includes public and private residences where older adults reside and are to be provided for their medical, psychological and social needs. The type families includes the eleven families that participated in this study who are living with dementia. Government organizations are those ministries, committees, local council offices, or governmental programs that deal specifically with the health and social care of older adults. Within each network, organizations are connected to either hospitals as a general organization, or a specific hospital.

Therefore, the hospitals type includes both the collective hospitals of a country, rarely outside of the capital cities, and individually indicated hospitals, and includes private, public and social security run hospitals.

Table 14 Number of organizations by type and country

	Guatemala	El Salvador	Honduras	Costa Rica	Panama	tot
Care Homes	11	4	3	1	2	21
Families	3	2	2	2	2	11
Government	12	17	8	11	4	52
Hospital	9	4	4	3	0	20
Non-profit	6	4	3	5	2	20
Private	5	6	4	5	4	24
Social Security	4	1	1	3	1	10
University	3	4	3	3	3	16
Totals	53	42	28	33	18	174

The non-profits type of node includes any association or organization providing services to older adults on a charitable status. For example, every country has a Human Rights organization, association or commission, which is non-profit and nongovernmental, as they also hold the responsibility of ensuring that governments protect and respect the human rights of their residents. Private enterprises are types of organizations, which are for profit and provide services to older adults for a fee. In every country included in this study, both public national health care and a detached form of governmental health system, known as social security exist. Social security health care is paid into through employment taxes. In Costa Rica, the social security health system covers every individual regardless of their employment status. Whereas in Guatemala, El Salvador, Honduras and Panama, an individual must be registered with the social security health system through their employment or as a spouse or dependant of a member. These social security types of organizations provide services to older adults such as direct care and day centres. Finally, universities are also a type of organization that was nominated both as a collective and individually.

The results of dividing the organizations involved in the networks by type and by country are shown in Table 15. Governmental organizations are the most

prevalent in four of five country networks. In El Salvador, Honduras and Costa Rica government institutes are almost double of any other type of node. In Guatemala, government type of nodes are also the majority, with care homes having nearly the same presence in the network. Government and private type nodes hold the same prominence in Panama. Government is very involved in providing services to older adults in these Central American countries. This can be viewed positively, implying that governments of these countries acknowledge this population's needs. Contrarily, the high number of government programs may suggest an authoritative control of provision of services and funding, thus restricting targeted service growth (Cruz 2015).

## Type of Tie

The type of tie bids a subjective categorization of the relationship between two organizations. The item in the interview guide asked "What type of relation is there between you and X (nominated organization)?"

Following three coding phases, the latter two illustrated in Table 16, responses from the five countries were grouped into nine categories that emerged: collaboration, human rights, regulate/complaints, political, medical attention, informal, by law, referral, education. Collaborative ties were the most prevalent in all five countries (Table 17) accounting for 41% of the 328 indicated types of tie. In Guatemala, Costa Rica and Panama collectively, 18 ties were multiplex, where respondents indicated a tie was more than one type. Fifty-five percent of El Salvador's ties were indicated as collaborative, 38% in Honduras, 37% in Costa Rica, 36% in Guatemala, and 29% in Panama.

As discussed in chapter 2, collaborative ties are the foundation of integration (Axelsson and Axelsson 2006, Bungler et al. 2014, Provan and Milward 2001, Beatá 2013); therefore, these findings suggest that integration is present on some level in the networks. The following analyses of the data explore this in more detail and depth and build up an analysis of integration by looking at the types of ties.

Table 15 Type of tie coding phases

Phase 2		Phase 3
support social responsibility / pgms collaborative/coordination/joint work assistance economic events professional	1	collaborative
human rights	2	human rights
monitor/regulate/supervise complaints	3	regulate
medical attention	4	medical attention
informal	5	informal
by law	6	by law
member political	7	political
referral	8	referral
education	9	education

Table 16 Type of tie by country

	1	2	3	4	5	6	7	8	9
Guatemala	44	2	10	6	21	0	2	4	33
El Salvador	51	0	8	3	6	1	11	3	10
Honduras	15	0	4	1	6	6	3	1	3
Costa Rica	16	0	1	1	6	9	4	2	4
Panama	9	1	4	0	2	5	3	2	5
<b>Total</b>	<b>135</b>	<b>3</b>	<b>27</b>	<b>11</b>	<b>41</b>	<b>21</b>	<b>23</b>	<b>12</b>	<b>55</b>

1: collaborative; 2: human rights; 3: regulate  
4: political; 5: medical attention; 6: informal  
7: by law; 8: referral; 9: education

## Type of tie and type of node

Collaboration and education emerged as the most frequent types of ties in the five networks, and government emerged as the most frequent type of node. This

section describes the analysis of the types of nodes within the types of ties (Table 18). Education was also a highly frequent type of tie cumulatively, but in only two countries it was actually highest in frequency. Accordingly, in addition to collaborative and education ties, the most prominent type of node was explored in each country's other most frequent types of ties. In Guatemala, most of the collaborative ties were between government organizations, meaning that both the interviewed nodes and the nominated nodes were government. In El Salvador, Honduras and Panama the majority of the collaborative ties were between non-profits and governmental organizations. In Costa Rica, the majority of collaborative ties were between privates and government. Among the educational ties, most in Guatemala were between the Alzheimer's Association and care homes.

Table 17 Type of node in type of tie by country

	GT		SV		HN		CR		PA	
<i>Type of Tie</i>	<i>Type of Node</i>									
	I	N	I	N	I	N	I	N	I	N
Collaborative	G	G	N	G	N	G	P	G	N	G
Education	A	AH	AH	U		U	P	G	P	U
Regulate			G	G						
Informal					S	G				
Medical Attn					U	H	G	G	P	GA
I = Interviewed N = Nominated										

In El Salvador between care homes and universities, while in Honduras the interviewed nodes' types were equally present but the majority of the nominated nodes were universities. Costa Rica's educational ties were mostly between private organizations and government and in Panama between private organizations and universities. The prominence of government organizations was highlighted as participating in collaborative ties in all five countries, most frequently with non-profits.

## Reciprocal ties

Reciprocity in a social network indicates some sort of balance or harmony, which can nullify the negative effects of social stratification (Bandyopadhyay et al. 2011). Reciprocity of the whole network is a measure of the integration of a networks' actors among themselves (ibid). In parallel, in the integrated care literature, reciprocity is emphasized as leading to effective joint working (Glasby and Dickinson 2014).

The norm of reciprocity is hypothesized to be universal. It is defined as a mutually contingent, gratifying exchange of benefits or services between two or more units (Gouldner 1960). In his statement *The Norm of Reciprocity*, Gouldner extricates the moral elements of the concept as a folk belief and a norm of obligations, which imposes a demand factor for people to 'return the favour' and to avoid damage to the person who has helped them. The status of the participants allows for variability in the obligations instituted by reciprocity. While equivalence takes the form of value or form and context, as Gouldner illustrates colloquially either 'tit for tat' or 'tat for tat'.

Within social systems such as the older adult networks I investigated, reciprocity has a three-fold significance. First, the norm of reciprocity introduces indebtedness into social relations, which leads to a motivation to conformity, or fulfilment of obligations. Second, reciprocity is highly subjective or contextual, thus it is flexible. It is a norm that can be applied to a wide array of exchanges and maintains social structures linked by providing a moral authorization in otherwise unregulated exchanges. Finally, reciprocity can form the beginnings of a social system. The norm acts as a starting mechanism of social interaction, sealing superficial relations by establishing the aforementioned mutual moral obligations.

Therefore, by applying the above attributes of reciprocity to the older adult networks of each country, reciprocity findings add to the measurement of integration by showing the actors in the networks that are linked by the exchange of mutual obligations. The norm of reciprocity provides the foundations for linkages between organizations to form, without the need of formal alliances or agreements. Furthermore, the existence of reciprocal ties where formal alliances are not present shows the initiation of a social system.

Table 18 Reciprocity matrix Honduras

	FEN	CIS	IH	D	F1	F2	CON	HSF	UNA	CS	CM
FEN			1	1							
CIS									1		
IH				1							
D	1								1		
F1											
F2			1								
CON											
HSF				1					1		
UNA				1							
CS											
CM			1						1		

To find reciprocal ties in the data, the following process was completed. A matrix for each country was created, including only the organizations that were interviewed on both the x and y-axes. Where an organization nominated another, a 1 was placed in the cell. This process was repeated for each organization along the row, placing 1s where the column head organization was nominated as shown in the reciprocity matrix in Table 19. For example, if organization A indicates it has a relation with organization B, it is not inherently implied that organization B has a relation to organization A. Only when organization B also indicates it has a relation with organization A can the tie be considered reciprocal. The total possible reciprocal ties are found by multiplying the total number of organizations interviewed  $n$ , by the total number of organizations in the network - 1,  $(n(n-1))$ . An organization cannot nominate having a relation with itself; therefore, the total number of organizations interviewed is multiplied by all of the organizations interviewed except 1, which represents a self-tie.

Reciprocity was low in all five countries. The total number of ties in all five countries that mutually indicated a connection were twenty-three of the total 368 ties in the region, or 6% of all ties were reciprocated (Table 20). Of Guatemala's 120 possibly reciprocal ties, 12 existed. In El Salvador 7 of the possible 120 reciprocities were indicated. Both Honduras and Panama claimed one reciprocal tie, of their networks' possible 55 and 28 respective reciprocities. Out of the 45 possible, Costa Rica's network showed two. Before drawing conclusions about



what this means for the networks it is important to look at the types of organisations (nodes), and the types of ties most commonly involved in reciprocal ties.

Table 19 Reciprocal ties of interviewed organizations by country

<b>country</b>	<b>reciprocal ties</b>	<b>possible reciprocals</b>	<b>reciprocity percentage</b>
<b>GT</b>	12	120	10%
<b>SV</b>	7	120	6%
<b>HN</b>	2	55	4%
<b>CR</b>	2	45	4%
<b>PA</b>	1	28	4%
<b>TOT</b>	24	368	7%

### Type of Node in Reciprocal Ties

All of the matrices of the reciprocal ties were labelled by node type then combined into one master matrix. Care homes, hospitals and social security agencies did not participate in any reciprocal ties in any of the five countries (Table 21). The Alzheimer's associations maintained the most reciprocal ties participating in a total of fourteen of the 23 total reciprocal ties in the five country networks. The Alzheimer associations were part of 8 reciprocal ties in Guatemala, 4 in El Salvador and 2 in Costa Rica. In Guatemala, 2 government agencies, one a regulator, reciprocated the Alzheimer's associations' ties, as well as the 3 families supported, the geriatrician providing services within the association, a university and the association for people with disabilities. The nodes receiving support from the association reciprocated the tie. In El Salvador 2 care homes who offer seminars for staff on Alzheimer's, and 1 which offers the association a free office space on their premise, reciprocated the ties with the Alzheimer's association. The human rights association that collaborates on mistreatment cases, and the memory clinic, director of which is on the board, also reciprocated the ties.

Similarly, in Costa Rica, the memory clinic, also on the board, and the gerontology association both reciprocated the ties with the Alzheimer's association.

Table 20 Type of node in reciprocal tie

		GT	SV	HN	CR	PA	tot
<i>Alzheimer Ass</i>	<b>A</b>	8	4		2		14
<i>Care Home</i>	<b>AH</b>						0
<i>Families</i>	<b>F</b>	3					3
<i>Government</i>	<b>G</b>	8	3	1		1	13
<i>Hospitals</i>	<b>H</b>						0
<i>Nonprofit</i>	<b>N</b>	1	6	1		1	9
<i>Private</i>	<b>P</b>	1	1		2		4
<i>Social Security</i>	<b>S</b>						0
<i>University</i>	<b>U</b>	3					3
	<b>tot</b>	24	14	2	4	2	46

Another node type highly frequently involved in reciprocation was governmental organizations, participating in 13 of the 23 reciprocal ties. Eight of these ties were in Guatemala, 3 in El Salvador, 1 in Honduras, and 1 in Panama. The one mutual tie both in Honduras and in Panama was between a government organization and a non-profit. Ties including government in Guatemala were with the regulating body of older adult care centres/homes, and the agency providing day centres. These agencies had reciprocal ties with each other, universities who offer students, and the human rights association, which monitors them.

The most ties reciprocated in El Salvador, 6, involved non-profits. These reciprocal ties involved the human rights association, a support provider, a care home and a pensioners association, all of whom either supervised the other or offered services.

Gouldner's (1960) definition of reciprocity is demonstrated in the above ties. Where there is an exchange of benefits or services, it is mutual and gratifying because the exchange allows for both organizations' needs to be met.

## Type of Tie in Reciprocal Ties

Within the forty-six reciprocal ties, 25, 54%, were labelled as collaborative.

Findings of four countries portrayed the majority of ties as the collaborative type: 36% in Guatemala, 86% in El Salvador, 50% in Costa Rica, and both ties in Panama, 100%. In Honduras, one of the two ties was labelled a political tie and the other a tie by law. This finding reflects the findings thus far, where collaborative ties are the most common type of tie. This will be further described in the following sections.

## Strength of Tie

Associations, organizations, and programs targeting older adults or more specifically older adults with dementia, are often thought of as being managed by teams of people. Thus gathering information from one individual representative about how strong ties are between two organizations may seem incomplete. Yet, where funding is scarce or possibly non-existent, as in many low to middle income countries like the Central American countries researched in this study, one individual makes up the organisation or plays a key part in representing it within the wider network, as described in chapter 5.

Following my semi-structured interview guide, for each connection an organization representative nominated, the interviewees were asked to rate that connection in three dimensions of strength: importance, strength and influence on a Likert scale of 0-10, as described in chapter 3. To reiterate from the methods chapter, strength of tie was defined as a subjective ranking of amount of time, frequency, duration, intensity, friendship, trust, commitment, and value of interacting. Influence was outlined as a subjective perception of the amount, frequency or quality of impact of any kind two organizations had on each other, while importance was the value, significance, and worth of the tie.

In analysis, strength ratings were grouped from the Likert scale 0-10 into three levels: 0-3 very low; 4-6 satisfactory; 7-10 very high. The number of ties rated in

each level paralleled the levels. The total number of ties, in all five countries, rated as very high (7-10) for the three dimensions importance, strength and influence made up 69% of all ties (Table 22). In the separate dimensions, eighty-five percent of all ties cumulatively in the five countries were rated very important. Fifty-nine percent of all ties were rated very strong, and 62% were rated very influential.

Table 21 Strength of tie by dimension, country and score

Likert scale scores		7-10			4-6			0-3		
COUNTRY	Tot Ties	IMP	STR	INF	IMP	STR	INF	IMP	STR	INF
Guatemala	110	<b>93</b>	55	62	13	39	21	4	15	26
El Salvador	93	<b>82</b>	66	64	8	18	17	3	9	12
Honduras	39	<b>31</b>	22	26	3	10	4	5	7	9
Costa Rica	41	<b>35</b>	30	28	5	6	8	1	5	5
Panama	27	<b>22</b>	10	12	1	7	5	4	10	10
TOTALS:	310	263	183	192	30	80	55	17	46	62

Eighteen percent of all ties were rated as satisfactorily (4-6 on the Likert scale) important, strong and influential. All five countries cumulatively rated 10% of ties as satisfactorily important, 26% of ties as satisfactorily strong, and 18% of all ties as satisfactorily influential.

Only 13% of all ties were rated of very low strength (0-3 on Likert scale). Within these 125 very low strength ties, 14% were rated of very low importance, 37% very low strength, and 50% of the very low strength ties were of very low influence.

### Type of Node and Strength of tie

The nodes that were interviewed were categorized into type of organization then all rankings they made of importance, strength, and influence of each tie they claimed, were summed by score group as described in chapter 3 (Table 23). The results reiterate the strong presence of governmental organizations in the networks that emerged through the aforementioned analysis of the types of nodes.

Very important, very strong and very influential rankings were given most frequently by governmental organizations, in the five countries as shown in Table

10. Ties were rated not important most frequently by private organizations, while ties were most frequently rated not strong and not influential by governmental institutions.

Table 22 Total strength of tie scores by type of node

GUATEMALA				EL SALVADOR				HONDURAS			
	7-10	4-6	0-3		7-10	4-6	0-3		7-10	4-6	0-3
A	44	22	0	A	26	5	2	A	0	0	0
AH	24	7	2	AH	30	9	12	AH	18	2	1
G	48	15	21	G	70	5	6	G	6	7	2
N	37	6	5	N	44	18	4	N	9	1	8
P	16	7	10	P	10	4	0	P	9	1	8
S	0	0	0	S	1	0	0	S	21	0	0
F	16	1	1	F	9	0	0	F	7	3	2
H	3	9	6	H	0	0	0	H	0	0	0
U	23	5	2	U	22	2	0	U	9	3	0
COSTA RICA				PANAMA				TOTAL 5 countries			
	7-10	4-6	0-3		7-10	4-6	0-3		7-10	4-6	0-3
A	16	4	1	A	0	0	0	A	86	31	3
AH	0	0	0	AH	0	0	0	AH	72	18	15
G	18	3	3	G	4	0	2	G	146	30	34
N	3	2	1	N	12	5	10	N	105	32	28
P	34	6	2	P	19	6	8	P	88	24	28
S	0	0	0	S	0	0	0	S	22	0	0
F	12	2	4	F	9	2	4	F	53	8	11
H	10	2	0	H	0	0	0	H	13	11	6
U	0	0	0	U	0	0	0	U	54	10	2

For each country, the type of node found in the highest ratings of the three dimensions of strength were accumulated. Government organizations emerged as the most frequent node to rate ties as very strong, 23% of very strong ratings were offered by government nodes. Government nodes in both Guatemala, 23%, and El Salvador, 33%, were also the most frequent raters of very strong ties. In Honduras, 27% of ties were rated very strong by social security organizations. Instead, in both Costa Rica, 37%, and Panama, 43%, private organizations most frequently rated ties as very strong.

The most very low strength ratings were given by a different type of organization in each country: government in Guatemala, care homes in El Salvador, non-profits and private in Honduras, families in Costa Rica, and non-profits in Panama. Cumulative very low strength included the three dimensions importance, strength and influence where most of the very low scores were given in influence. It could be expected that government agencies ranked ties as hardly influential in Guatemala, because they are the authority within the tie thus are not influenced by the node they connect to. A parallel explanation for care homes in El Salvador ranking ties as very low in the strength domain, again is the very low influence dimension that carries the highest score, where care homes do not receive funding from other nodes, nor are regulated by nodes other than government. The same can be applied in the other countries, very low influence playing the largest role in very low strength scores. Privates and non-profits in Honduras, families in Costa Rica and non-profits in Panama, provided very low scores where they felt their practices or lives were not changed in any way by their ties to other nodes. The majority of these ties offering very low strength scores were not reciprocal ties, which recapitulates the benefits of reciprocity.

### Type of tie and strength of tie

To complete this analysis of strength of tie by type of tie, only very strong ties, in any of the three dimensions, were included because they represented the majority of the ties. The most frequent type of tie in the very strong ties was collaborative. Cumulatively in the five countries, 45% of very strong ties were labelled as collaborative ties. Forty percent in Guatemala, 56% in El Salvador, 39% in Honduras, and in both Costa Rica and Panama 41% of ties were collaborative. These findings matched the general findings that showed the most frequent type of ties in the networks were collaborative.

### Strength in reciprocal ties

In a reciprocal tie, importance, strength, and influence were ranked by each node. These rankings on a Likert scale from 0 to 10 were grouped into 3 groups of very high, medium and very low. These ranking groups were compared in order to

understand if the actors were in agreement or disagreement on the importance, strength and influence of the tie. For example, in Guatemala a university and a governmental agency had a reciprocal tie where the university ranked the tie a 'very high' in all three dimensions of strength. However, the governmental agency ranked the tie with the university medium and very low on strength and influence respectively. In this case, the actors of this reciprocal tie had different opinions on the strength of their tie. It is plausible that a university does not influence a government agency providing services to older adults, and that the tie in the government agency's perspective is not as strong, as the two may not communicate or collaborate often. It is also plausible that from the university's perspective, a government agency is highly influential in regulating their work and thus considers the tie high in strength.

It would be expected that organizations with ties to government agencies would rank those ties as very strong in all three dimensions because of the authoritative position of government. It would also be expected that governmental agencies rank their ties to community organizations as medium or low total strength because they may supervise and monitor, yet may not collaborate or communicate actively. Furthermore, governmental agencies' policies and processes are not directly influenced by community organizations.

Almost half of the reciprocal ties, twelve of the twenty-three ties, had diverging rankings. Within these 12 in fact, governmental agencies ranked the strength of the ties lower than their counterparts did in eight reciprocal ties. One of these ties was between 2 government agencies and each ranked the other lower, one in one element, the other in two elements. Non-profits also gave lower scores than their reciprocal counterparts on the strength of four ties, while the Alzheimer's associations provided lower scores in one tie. These differences in scores highlight how perspective affects relations. Although reciprocal, the two organizations involved in an interaction may have different inputs and outputs, as exemplified in the next section.

# Exchange

The exchange perspective, derived from organizational theory, bases the involvement of organizations in a network on the potential advantages and disadvantages such as gains and losses in power, costs, and resources (Provan and Milward, 1995). It follows that cooperation and joint working depend on exchange. In an integrated care scenario, as the biopsychosocial care model outlines, sharing information about an older adult with complex needs amongst the service providers leads to quality and continuity of care (Borrell-Carrio et al. 2004, Keady et al. 2012, Engel 1977, 1980, 1997, Nicaise et al. 2013) Consequently, highlighting what is being exchanged allows for an understanding of what is valued by the network, what is the glue that maintains the network connections, and finally if the network can provide that integrated care.

Two items of the interview guide inquired about exchange: interaction and flow. The question I asked the interviewees for the interaction element was:

*“How do you help each other or what do you speak about?”*

For the flow element, I asked:

*“What do you exchange?”*

I describe these two separate elements in the same section because during analysis the overlap became evident. Category coding of the responses was completed in three phases. The first phase comprised coding each country's responses into sub-categories. Phase 2 incorporated combining country sub-categories revealing twenty-two categories of interactions and 18 of flow, as illustrated in Figure 11. In this phase, the emerging categories within the two dimensions were strikingly similar and obviously overlapped, which motivated the search for evidence in the literature that would justify uniting them.

Social exchange theory explains social interactions as based on exchange (Emerson 1976, Foa and Foa 2012, Blau 1964). Ergo, how organizations interact and what flows between them became the inclusive attribute exchange.



Figure 11 Phase 2 exchange coding

Exchange Phase 2: 37 Categories	
<u>INTERACTION</u>	<u>FLOW</u>
abandonment / abuse	advice
activities	coordination
agreement	dialogue
awareness	education
collaboration	events/activities
complaints	experiences
conference	info
coordination	joint/ collaboration
escort	knowledge
info	legal
infrastructure	practicum
judicial	pt. services
knowledge	referral
medical attn.	research
plan / organization	resources
practicum	support
referral	
regulate / supervise	
resources	
support	
training	

Figure 12 Phase 3 exchange coding

Exchange Phase 3: 5 Categories				
<u>INFO</u>	<u>REFERRAL</u>	<u>RESOURCES</u>	<u>COLLABORATION</u>	<u>NOTHING</u>
abandonment/	referral	escort	activities	none
abuse		infrastructure	agreement	nothing
advice		knowledge	conference	
awareness		medical attn.	coordination	
complaints		practicum	dialogue	
information		pt. services	events/activities	
judicial		research	experiences	
legal		resources	collaboration	
		training/edu	plan/organization	
			regulate	

Phase three of coding entailed aggregating the interaction and flow elements' thirty-seven categories (Figure 12). Linked to the above-mentioned integrated care scenario, in the literature of system level social network analysis of organizations, flow and exchange categories are used as indicators in assessing integration. Raeymackers (2013) identifies information, referral and case

coordination. Blanchet and James (2012) base their analyses on information exchange. Wang et al. (2016) evaluate referral, information, and joint training. Rosenheck et al. (2000) and Morrissey et al. (1985, 1994) examine the sharing of information, clients and funds. Provan and Milward assess linkages of referral, case coordination, joint programmes, and service contracts in a 1995 study, and exclude service contracts in a 1998 study. These indicators guided phase three of coding, the reviewing of themes as described in chapter 3, and later, the assessment of network integration.

The outcomes of the third and final phase were, based on the above indicators, five main categories of exchange: information, referral, resources, collaboration, and nothing. In the next section, each of the five exchange categories will be described and findings for each will be outlined.

## Information

Findings in the exchange of information began with seven sub-categories that were merged into the information category. Advice, legal advice, information, abandonment and abuse information, complaints, judicial, and awareness all capture a kind of information, thus consolidated into the information type of exchange. Of these sub categories, ties in El Salvador and Honduras exchanged legal and judicial information and advice more than other countries and in Costa Rica and Panama not at all. Costa Rica's ties did not exchange complaints. Ties did not exchange abandonment and abuse information nor advice in El Salvador and Costa Rica.

Table 23 Information exchange scores

Information exchange	
<i>country</i>	<b>INFO</b>
<b>GT</b>	73
<b>SV</b>	43
<b>HN</b>	16
<b>CR</b>	14
<b>PA</b>	9

Information was claimed to be shared in 155 ties, 50% of the 310 total ties of the five countries. Table 23 shows in Guatemala 66% of ties exchanged information, 46% in El Salvador, 41% in Honduras, 34% in Costa Rica and 33% in Panama. These findings contradict the findings from Bunn et al (2017), that sharing information across disciplines was unsustainable, in a study on healthcare organisation and delivery, where participants included families with dementia. The difference could depend on context, Bunn et al.'s study was conducted in the South and North East of England, UK, which includes a culture based on exchange to sustain poorly funded services as described subsequently.

## Referral

Compared to the other categories, referrals were seldom exchanged. This category was made up of explicit referral responses and responses indicative of a referral such as the sharing of patients, cases, placements and requests for medical visits. Every one of the five countries had three or more ties exchanging referrals (Table 24).

Table 24 Referral exchange scores

Referral exchange	
<i>country</i>	<b>REFERRAL</b>
<b>GT</b>	28
<b>SV</b>	24
<b>HN</b>	7
<b>CR</b>	9
<b>PA</b>	4

Twenty-five percent of Guatemalan ties, 26% of Salvadorian ties, 18% of Honduran, 22% Costa Rican and 15% of Panamanian ties made referrals. In sum, 23% of ties exchanged referrals in the five countries. This finding indicates that organizations within the networks seldom refer their clients, patients, or families in general to other nodes in the networks. This could imply competition between nodes or a lack of knowledge regarding what services other nodes in the network offer.

## Resources

Foa and Foa (2012) lay out the six types of resources exchanged in social interactions according to resource theory: love, status, info, money, goods, and services. The data of this study led to nine types of resources exchanged (left column Table 15). Within those, the resources type was previously coded into a small category of its own, where the explicit word resources was a response in itself, and included other six responses (Table 15). Love and status did not emerge from the data, most likely because the social interactions investigated in this study were business ties between organizations. Otherwise, the data confirms the types of resources exchanged by resource theory.

Figure 13 Resources theme of exchange

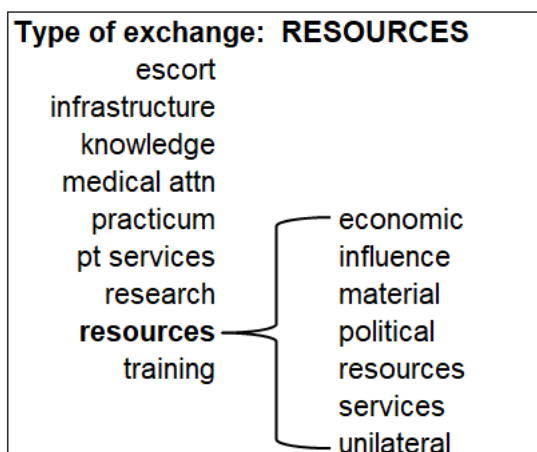


Table 25 Resources exchange

Resources exchange	
<i>country</i>	<b>RESOURCES</b>
<b>GT</b>	95
<b>SV</b>	80
<b>HN</b>	27
<b>CR</b>	33
<b>PA</b>	20

As aforementioned, the total number of ties in the five countries was 310. Of these, 82% of interactions exchanged resources. Table 25 outlines the number of ties exchanging resources per country. A deeper look into ties exchanging resources follows in the section describing multiplex ties below.

## Collaboration

Joint working can manifest in a variety of ways. Developing, implementing, coordinating and participating in projects, events and activities resulted as a

common form of collaboration between organizations. Conferences, celebratory occasions, and excursions are also experiences where cooperation is exchanged, thus these responses were included in the collaboration category. From the total thirty-seven categories of exchange that emerged from the responses of types of interaction and types of flow, ten sub-categories were consolidated into the collaboration category (Table 26).

Table 26 Number of responses in collaboration subcategories

<b>Type of exchange: COLLABORATION</b>						
	GT	SV	HN	CR	PA	Tot
activities	5	4	1	1	1	12
agreement	1	1	1	1	1	5
collaboration	45	47	22	22	22	158
conference	1	1	1		1	4
coordination	1	5		1		7
dialogue					6	6
events/activities	8	7	3	3	1	22
experiences			4			4
organization	1			1		2
regulate	2	1		6	1	10

The analysis of the sub-categories outlined the following country specific findings (Table 26). In all countries, organizations most frequently declared to exchange collaboration, events and activities. The former sub-category was the most exchanged via responses using the exact words, and teamwork, assistance, research, projects, intergenerational exchange, relations, roundtable, and support. The events and activities sub-category emerged directly from interviewees replying with the exact words events and/or activities.

Ties that shared experiences were found only in Honduras, and dialogue only in Panama. Coordination was exchanged in two of the five countries, El Salvador and Costa Rica. The latter is the only country where ties did not declare exchanging collaboration in conferences. Only Guatemala and Costa Rica's ties exchanged planning and organization skills. Finally, regulation and supervision was not claimed to be exchanged in Honduras.

Table 27 Collaboration exchange scores

Collaboration exchange	
<i>country</i>	<b>COLLAB</b>
<b>GT</b>	38
<b>SV</b>	59
<b>HN</b>	17
<b>CR</b>	21
<b>PA</b>	16

As a sub-category of exchange, 151 ties of the total 310 of the five countries, 49%, indicated they collaborated. As portrayed in Table 27, 35% of ties exchanged collaboration in Guatemala, in El Salvador 63%, Honduras 44%, in Costa Rica and Panama 51% and 59% respectively.

### Nothing

Where organizations claimed to exchange nothing in reply to both questions of interaction and flow, the tie was categorized as an exchange of nothing.

Table 28 Nothing exchange scores

Nothing exchange	
<i>country</i>	<b>NOTHING</b>
<b>GT</b>	2
<b>SV</b>	3
<b>HN</b>	3
<b>CR</b>	3
<b>PA</b>	4

Table 29 Ties exchanging nothing by type of node

<b>GT</b>		<b>SV</b>		<b>HN</b>		<b>CR</b>		<b>PA</b>	
<i>int</i>	<i>no</i>	<i>int</i>	<i>no</i>	<i>int</i>	<i>no</i>	<i>int</i>	<i>no</i>	<i>int</i>	<i>no</i>
G	U	G	G	N	N	A	G	N	G
N	S	G	N	N	S	F	G	N	S
		G	N	N	A	P	A	AH	G
								AH	G

*int = interviewed, no = nominated*

Fifteen ties within the five countries claimed to not engage in exchange (Table 28). Of the total ties of the five countries 310, the nothing category accounts for 5%. Nothing was exchanged in 2 Guatemalan ties, 3 Salvadoran, Honduran and Costa Rican ties, and 4 Panamanian ties (Table 19).

Ties that exchanged nothing chiefly included non-profits and government types of organizations (Table 29). Approximately 70% of these ties were also ranked as very low in strength and influence; nevertheless 60% were ranked very high in importance. Furthermore, 5 of the 15 were categorized as the collaborative type of tie, and another 5 were related by law, 3 of which included government nodes and 1 social security node. Two ties were the regulate type, 1 political tie and another no type was given. Although ties exchanged nothing, a relation existed.

The findings demonstrate that change between organizations was a common practice that is further underlined in the next section where findings portray ties interacting in multiple exchanges.

## Multiplex Ties

Morrissey et al. (1994) explain that recognizing only one type of exchange as a “meaningful relationship” (p61), may be a flawed interpretation. They suggest that one type of exchange alone such as information sharing, could be interpreted as organization dumping or uncoordinated care. By combining the data, the focus moves to multiplex ties such as exchange of three types of exchange: information, referrals, and resources, abbreviated as IFR. “In social network research multiplexity refers to the extent to which two actors are linked together by more than one relationship in a network” (Ferriani et al. 2012, p7). Milward and Provan (1998) characterize the accumulation of types of interaction as “gauging depth of involvement” (p393). Organizations cooperating through more than one type of exchange would therefore be more involved in the network.

Through a second analysis of the exchange category, ties were labelled according to any and all of the types of exchange claimed. The sub-categories or types of exchange were labelled I-information, F-referral, R-resources, and C-collaboration.

Responses from interviewees of what was exchanged between two organizations revealed instances of two or more things being exchanged. Each type of exchange was labelled independently then consolidated to disclose multiplex categories of exchange. Eleven combinations of exchange, or types of multiplex ties, are possible: IFRC, IFR, IFC, IRC, FRC, IF, IR, IC, FR, FC, RC (Table 30).

Table 30 Multiplex ties

<b>Types of Multiplex Ties</b>	
IFRC	IF
IFR	IR
IFC	IC
IRC	FR
FRC	FC
IF	RC

Table 31 Multiplex ties by type

	GT	SV	HN	CR	PA	TOT
<b>IFRC</b>	3	7	1	0	0	11
<b>IFR</b>	16	3	1	2	1	23
<b>IFC</b>	0	5	0	2	1	8
<b>IRC</b>	17	18	3	6	7	51
<b>FRC</b>	1	1	0	3	1	6
<b>IF</b>	3	0	4	0	0	7
<b>IR</b>	28	9	4	3	0	44
<b>IC</b>	5	1	2	1	0	9
<b>FR</b>	4	6	0	0	1	11
<b>FC</b>	0	1	1	1	0	3
<b>RC</b>	12	24	9	8	5	58
<b>TOT.</b>	89	75	25	26	16	231

Of the 310 total ties of the five countries, 231 were multiplex, 75% (Table 31). Resources together with collaboration, RC, emerged as the most frequent multiplex tie, accounting for 58 of the 231 multiplex ties, 25%. The combination



IRC emerged in 51 ties sharing information, resources and collaboration, accounting for 22% of the multiplex ties. A similar portion of ties, 44, shared information and resources, IR, 19%. Resources was the type of exchange present in the three of the most frequent multiplex ties. Resources was also the most frequent type of independent exchange, illustrated previously. Within each individual country, the most frequent multiplex ties differ somewhat. In Guatemala, information combined with resources was the most common multiplex tie assuming 31% of the multiplex ties. In El Salvador, Honduras and Costa Rica most multiplex ties shared resources and collaboration, RC, 32%, 36% and 31% respectively. IRC, information, resources and collaboration was the most frequent multiplex tie in Panama accounting for 44% of multiplex ties. Again, resources is repeated in the most frequent multiplex ties, in addition to on a regional level, on the individual country level as well. The findings demonstrate that the exchange of resources could be the mode of existence of the older adult and dementia services, which will be discussed in chapter 8.

#### Exchange in reciprocal ties

The patterns of exchange within the reciprocal ties mirror the patterns of the ties in general. Among the reciprocal ties, unilaterality was visible. In eighteen of the 46 reciprocal ties, 39%, the types of exchange differed. In three of the eighteen ties one of the nodes exchanged information while the other did not. Only one node exchanged referrals. In three ties, resources were exchanged unilaterally and in 5 ties collaboration.

The other twenty-eight reciprocal ties, 61%, reciprocated the same types of exchange. Twenty-four exchanged information, 9 referrals, 38 resources and 29 collaboration. Similar to the general findings of all of the ties, resources were exchanged between 83% of the ties. Types of ties and nodes of these reciprocal ties were described previously and will be aggregated in the conclusion of this chapter.

## Multiplexity in reciprocal ties

Findings of the reciprocal ties also mirror the general patterns of multiplexity where the same three types of multi-relations feature. Information, resources and collaboration, IRC, account for 8 of the 46 ties; information and resources, IR account for 7; and 9 ties exchange both resources and collaboration.

Table 32 Multiplex exchange by type of node

Total types of nodes in multiplex ties						
node	GT	SV	HN	CR	PA	Tot
<b>A</b>	17	7	0	7	1	32
<b>AH</b>	6	1	4	0	0	11
<b>G</b>	40	51	9	10	5	115
<b>N</b>	18	15	6	3	6	48
<b>P</b>	11	17	2	7	6	43
<b>S</b>	3	3	4	1	0	11
<b>F</b>	5	2	1	3	2	13
<b>H</b>	3	2	1	1	0	7
<b>U</b>	10	4	5	2	4	25

As shown in Table 32, within the most prominent multiplex groups the greatest number of ties involve governmental organizations in four of the five countries. Governmental nodes accounted for 38% of the organizations involved in the 306 multiplex ties and specifically 44% of IRC ties, 23% of IR ties, and 43% of RC ties. El Salvador emerged with government participation at 50%, Guatemala at 35%, Honduras 28%, Costa Rica 29%, and Panama 21%. Non-profits and private organizations appeared to participate most in Panama at 25% each, as well as governmental agencies accounting for 21% of multiplex ties. The pattern of a high frequency of government nodes is consistent with the aforementioned findings of the type of node present in the networks. Of these multiplex ties that include government nodes, ten of the thirty-three IRC ties are between government and non-profits. In the 18 IR multiplex ties including government nodes, 5 are with other government nodes and another 5 with Alzheimer's associations. Lastly, of the 38 RC ties that include government, 16 are between two government nodes.

## Type of tie in multiplex exchange

The collaborative type was the most frequent type of tie in all types of exchanges with the most in the multiplex tie IRC: information, resources, collaboration.

Table 33 Collaborative type in multiplex tie

Percentage of collaborative type of tie in multiplex exchange									
GT		SV		HN		CR		PA	
IR	32%	IRC	24%	FRC	19%	FRC	19%	IRC	33%
		RC	24%	RC	19%	RC	19%		

Only in Guatemala did the majority of collaborative ties not exchange collaboration, instead information and resources were exchanged (Table 23). In El Salvador, the majority of collaborative ties were the IRC and RC multiplex ties exchanging information, resources and collaboration and the other type resources and collaboration (Table 33). Both Honduras and Costa Rica's collaborative ties were the FRC and RC multiplex types of exchange, while Panama the IRC (Table 23).

## Strength of tie and exchange

The ties labelled as very strong, using the cumulative scores of the three dimensions of strength, were most frequently multiplex ties RC, exchanging resources and collaboration, 26%. Also prominent in the very strong ties was the multiplex exchange IRC: information, resources and collaboration. In the individual countries, very strong ties most frequently exchanged information and resources, 30% in Guatemala, resources and collaboration in El Salvador (34%), Honduras (39%), and Costa Rica (32%), and in Panama information, resources and collaboration (44%).

To understand what was exchanged amongst the ties labelled the least strong, the very low influence ranked ties, which accounted for 50% of the total very low strength scores, were investigated. Forty-five percent of the very low influence

ties exchanged resources: 44% in Guatemala, 33% in El Salvador, 50% in Honduras, 57% in Costa Rica, and 63% in Panama. Therefore, the strength of the tie did not affect exchange.

## Dementia specific findings

As aforementioned in the methods section, the organizations that supported families with dementia either specifically or tailored their services to be able to provide services to them, or were families with dementia, were grouped as dementia specific. Examples of organizations excluded from this category are: care homes or day centres with explicit admission criteria denying access to individuals with cognitive impairments; pensioners' associations that offered activities and events for independent individuals; and nominated organizations where data was not available with regards to supporting families with dementia or not.

This group of nodes made up 56% of the organizations in the 5 network (Table 34), and 68% of the total ties, portraying a service system aware of the needs of families with dementia. These findings will be described in the following subsections and discussed in chapter 8.

Table 34 Number of dementia specific organizations in networks

Dementia specific org					
GT	SV	HN	CR	PA	tot
26	16	20	17	11	90

Eighty-nine percent of the organizations interviewed offered services for families with dementia, including families who not only may have received support but also gave it as they took care of their loved ones living with dementia. Within the individual countries, the range was between 43% and 67% of dementia support organizations. As specified in Table 24, of the 48 organizations offering older adult services in Guatemala 54% either tailored their services to include clients

living with dementia or specifically targeted families with dementia. In El Salvador 43%, in Honduras 67%, in Costa Rica 61% and in Panama 61%.

## Type of Node

The most represented type of node in the dementia specific groups was families, across the five countries. The number of families included from each country was deliberate and intended to be a small representative sample of the position of families in the service systems.

Table 35 Interviewed dementia specific orgs by type of node

Type of org	GT	SV	HN	CR	PA	tot
<b>Alz Ass</b>	1	1	1	1	0	4
<b>Care Homes</b>	2	1	1	0	1	5
<b>Families</b>	3	2	2	2	2	11
<b>Government</b>	2	0	1	1	0	4
<b>Hospital</b>	2	0	0	1	0	3
<b>Non-profit</b>	1	3	1	2	1	8
<b>Private</b>	3	1	3	2	2	11
<b>Social</b>	1	1	2	0	0	4
<b>University</b>	1	1	1	1	1	5
Totals	16	10	12	10	7	55

The most represented types of nodes were families and private organizations, both accounting for 11 of the 55, or 20%, of all the dementia specific nodes (Table 35). Non-profits, accounted for 15% of organizations offering services to families with dementia. The least represented types of nodes in the dementia specific networks were hospitals, 5% of all nodes. Governmental organizations and Alzheimer's associations both represented 7% of all nodes. It is important to note that it is customary there be one Alzheimer's association per country, or in larger countries, there are central associations with subsidiaries. Therefore the result of the number of Alzheimer's Associations can only underline that one country does not have (an operative) one.

## Type of Tie

The total number of ties of the five country networks that included a dementia specific organization were 211 of the total 311, 68%.

Table 36 Dementia specific types of ties

tie type codes	1	2	3	4	5	6	7	8	9
Guatemala	29	1	7	0	16	0	1	4	27
El Salvador	32	0	4	2	6	0	0	3	8
Honduras	11	0	4	1	6	6	1	1	3
Costa Rica	10	0	1	1	5	4	3	1	0
Panama	5	1	3	0	2	5	0	2	4
<b>TOTALS</b>	<b>87</b>	<b>2</b>	<b>19</b>	<b>4</b>	<b>35</b>	<b>15</b>	<b>5</b>	<b>11</b>	<b>42</b>

1 collaborative                      6 by law  
 2 human rights                      7 political  
 3 regulate                              8 referral  
 4 medical attention                  9 education  
 5 informal

In parallel with the general findings, in the dementia specific networks the most frequently claimed type of tie was collaborative (Table 36). Eighty-seven of the 211 ties, 41%, were labelled as based on collaborative. In Panama, the same number of collaborative ties were labelled medical attention ties. Thirty-four percent in Guatemala, 58% in El Salvador, 33% in Honduras, 40% in Costa Rica and 23% of ties in Panama were of the collaborative category.

## Reciprocal ties

Of the interviewed ties, which could confirm reciprocity, of 193 possible reciprocal ties within the dementia networks, 16 were reciprocated (Table 37). Seven in Guatemala, 6 in El Salvador, 1 in Honduras, 2 in Costa Rica, and 0 in Panama.

Table 37 Reciprocal ties of interviewed dementia specific organizations

Reciprocal dementia specific ties (interviewed)			
country	reciprocal ties	possible reciprocals	reciprocity percentage
GT	7	66	11%
SV	6	55	11%
HN	1	36	3%
CR	2	21	10%
PA	0	15	0%
<b>TOT</b>	<b>16</b>	<b>193</b>	<b>8%</b>

## Strength of Ties

For each tie including a dementia specific organization, the three dimensions of tie strength were scored as previously described: importance, strength and influence.

Table 38 Strength scores for dementia specific ties by dimension

Likert Scale	GT			SV			HN			CR			PA		
	<i>Imp</i>	<i>Str</i>	<i>Inf</i>	<i>Imp</i>	<i>Str</i>	<i>Inf</i>	<i>Imp</i>	<i>Str</i>	<i>Inf</i>	<i>Imp</i>	<i>Str</i>	<i>Inf</i>	<i>Imp</i>	<i>Str</i>	<i>Inf</i>
0-3	3	7	14	3	7	8	3	4	6	1	3	4	3	4	5
4-6	12	33	18	5	10	10	3	6	7	4	3	4	1	6	3
7-10	64	39	47	47	38	37	27	23	20	20	19	17	15	9	11

*Imp= importance; Str= strength; Inf= influence*

Scores were again grouped by the Likert scale responses 0-10, very high to medium to very low (Table 38). Sixty-eight percent of ties were rated an aggregate very high score, indicating the ties to be ranked very strong. These findings reflect the general findings of strength of ties, as do the very low strength scores that are most frequent in the influence dimension.

## Exchange

Reflecting the general findings, exchange between dementia specific ties featured resources (Table 39).

Table 39 Exchange scores of dementia specific ties

	I	F	R	C
<b>GT</b>	54	24	69	21
<b>SV</b>	23	13	50	30
<b>HN</b>	16	7	24	15
<b>CR</b>	7	4	21	11
<b>PA</b>	7	4	16	10
<b>tot</b>	107	52	180	87

Table 40 Multiplex exchange in dementia specific ties

	GT	SV	HN	CR	PA	tot
<b>IFRC</b>	2	3	1	0	0	6
<b>IFR</b>	16	1	1	0	1	19
<b>IFC</b>	0	2	0	1	1	4
<b>IRC</b>	9	9	3	5	5	31
<b>FRC</b>	0	1	0	2	1	4
<b>IF</b>	2	0	4	0	0	6
<b>IR</b>	20	8	4	1	0	33
<b>IC</b>	4	0	2	0	0	6
<b>FR</b>	3	5	0	0	1	9
<b>FC</b>	0	1	1	0	0	2
<b>RC</b>	7	12	7	4	3	33

Eighty-five percent of the total 211 ties in all five countries, which included a dementia specific organization, exchanged resources. The same combinations of multiplex ties were prominent as in the general findings (Table 40): resources and collaboration, RC, information and resources, IR, and information, resources and collaboration, IRC. Of the 153 total multiplex ties, RC and IR both accounted for 22% of multiplex ties, and IRC 20%. In each individual country, the largest portion of multiplex ties contained resources. In Guatemala 32% was IR, RC was the largest portion in both El Salvador and Honduras at 29% and 30% respectively, and in Costa Rica and Panama IRC was the largest portion at 38% and 42% respectively. Of the total two hundred and eleven ties in the dementia specific networks, nothing was exchanged in six of them, 3%. One in Guatemala between



two non-profits; 3 in Costa Rica between a non-profit and government, a non-profit and a private, and a family and government; and 2 in Panama between a care home and two government agencies.

## Conclusion

This chapter described the classification of the data into six attributes of the nodes and ties: the types of nodes that are in the networks, the types of ties that exist between the organizations, the reciprocal ties where both nodes nominate having a tie with each other, the strength of the ties between the nodes, what is exchanged among the nodes, and the dementia specific ties. Additionally, the findings of each attribute have been outlined and will be summarised here.

The five networks mainly consisted of 85% very strong, 41% collaborative ties, chiefly involving 29% governmental and 19% non-profit type nodes, most frequently exchanging 82% resources and 25% a combination of resources and collaboration.

Guatemala and Panama differ from the general findings in the most frequent multiplex exchange. Where the other countries most frequently exchanged resources and collaboration, Guatemala's ties exchanged information and resources, while Panama's ties exchanged all three: information, resources and collaboration. Representatives of organizations in both Guatemala and Panama claimed that the exchange of information was as frequent as that of resources. Information about a family member with dementia was most often exchanged in Guatemala, while the majority of responses in Panama were the exact word information.

The group of reciprocal ties, 7%, were 54% collaborative ties, 78% exchanging resources and 20% resources and collaboration jointly, 30% included the Alzheimer's associations and though the majority of the ties were rated very strong, 52% of nodes ranked the reciprocal tie differently.

Individually, the most frequent type of node in each country's reciprocal ties differed. Only Honduras and Panama's networks of reciprocal ties were similar,

including one of each government and non-profit type of node. Non-profits were most frequent in El Salvador's reciprocal tie network, and in Guatemala's the Alzheimer's association and government were most involved. Although these findings are limited, if more organizations of the networks had been interviewed reciprocity levels may have been higher, government and non-profits reciprocate most. The Alzheimer's association is a non-profit although in its own category to specify understanding of reciprocity. These findings signify that government agencies value the work of non-profits and the benefits received from them, thus reciprocate to maintain the exchange active.

Amongst the very strong ties, the most frequent type of node also differed from the general findings in Honduras, Costa Rica and Panama. The majority of very strong ties included a social security node in Honduras, and private nodes in both Costa Rica and Panama. Private organizations and non-profits also were most frequently involved in the exchange of resources in Panama, while in the other countries government nodes were most prominent. These findings highlight that Panama's network includes the least amount of government nodes, which may indicate less government involvement in older adults' health and social care. Alternatively, the low rate of participation of government could be explained by the limits of this study completing eleven interviews in Panama compared to 17 in Guatemala for example. Nevertheless, Panama's network stands out from the others as being mainly private and non-profit organizations.

Eighty-nine percent of the organizations interviewed were dementia specific, accounting for 56% of the total nodes in the networks, and 68% of the total ties. Families, non-profits and privates were the most frequent type of dementia specific nodes. El Salvador's dementia specific network differed from the general findings in the most frequent type of node: non-profits. Tie types, exchange, and strength mirrored the general findings: 42% collaborative ties, 85% exchanged resources, and 68% were rated as very strong ties. Reciprocal ties were also low amongst dementia specific nodes accounting for 8%.

The aim of this research was to explore the dementia specific networks of the five countries. The findings show that the majority of the organizations interviewed were dementia specific. The findings also clearly indicate that government

organizations lack in supporting families with dementia. Although government represented the majority of the nodes in the networks, only four government agencies tailored services to include provision to older adults with dementia.

In the next chapter, the findings from analyses of the network properties will be described. Eleven networks emerged in each country from the findings illustrated in this chapter, and their properties were analysed and compared. The measures of four network properties act as additional indicators of integration and provide further insight into the structure of the Central American older adult and dementia service systems.

# Chapter 7: Collaborating

## Introduction

Following the exploration of the individual organizations in chapter 5, the categorization of those organizations, and the findings about the interactions between them were described in chapter. 6. In this chapter, the view is fully enlarged to feature the networks. Network measures are characteristics specific to a set of organizations and their interactions, measurable with specific software programs, as described in the methods chapter. These measures act as further indicators of the level of integration present within the older adult service delivery systems. Joined with the findings of the types of ties and types of exchanges, conclusions will be drawn in the discussion chapter, as to the levels of integration of each country's system.

In this chapter, the focus becomes the network. In the previous chapters, the term system was used to signify all of the organizations in one country providing services to the specific population, older adults and families with dementia. The term network is used in this chapter to mean all of the organizations in a system, and all of the ties between them.

This chapter describes the measures of the networks. The main research question underlying this study investigates integration levels of the networks. As outlined in the methodology chapter, using social network analysis to analyse the ties between the organizations of the networks offers indicators of integration. Four measures were used to analyse levels of integration: density, closeness centrality, E-I index, and QAP correlation. The term integration indicator will be used to indicate these measures. Each integration indicator, and how it relates to integration and integrated care, will be explained in the respective sections in this chapter.

As outlined in Chapter 6, the coding of the data collected from the interviews was sorted into six distinct node and tie attributes: types of nodes that are in the networks; types of ties that exist between the organizations, reciprocal ties where both nodes nominate having a tie with each other, the strength of the ties between the nodes, what is exchanged among the nodes, and dementia specific ties. Following on these findings, the networks the networks, based on the six attributes, plus the exchange sub-attribute of multiplex exchange ties, were analysed for network measures.

Networks analysed for each country:

1. The Whole Network: all ties
2. Type of Tie: collaborative ties
3. Strength: total high strength ties (high importance+high strength+high influence)
4. Reciprocal ties
5. Dementia Specific ties
6. Multiplexity Exchange ties:
  - a. IRC: Information + Resources + Collaboration
  - b. RC: Resources + Collaboration
  - c. IR: Information + Resources
7. Exchange ties:
  - a. I: Information
  - b. F: Referrals
  - c. R: Resources
  - d. C: Collaboration

Each network listed encompasses a set of organisations that have specific ties to one another. For example, in the collaborative type of tie network, the ties included are those declared as being collaborative type ties between two organizations. Thus, the integration indicators of this network describe the organizations interacting in those specific ties. In the case of exchange, the networks analysed include only the ties declared as engaging in at least one specific exchange, such as information, between two organizations. As mentioned above, these networks were selected for analysis based on these specific

categories emerged in the findings, as outlined in the node and tie attributes chapter.

In the following sections, the findings for each integration indicator will be described through a cross-country comparison. A final summary for each country is provided at the end of the chapter.

## Whole Networks

The term whole network indicates a multi-organizational interactive social system providing services to a shared group of people. The outcomes of the network as a whole are considered rather than outcomes of the individual organizations that make up the network. The purpose of this macro-level view is to explore the structure and processes of the organizations together as a whole (Provan & Fish 2007).

Through a person centred care lens, the person receiving health and care services is a whole with complex needs requiring support from various sources. Therefore, the network and the person living with dementia are parallels, as are a person's multiple dimensions and a network's multiple service providers. The main idea of this thesis is that network parts must work together to provide integrated care that will support the multiple needs of the person with dementia.

In this subsection, visuals of each country's whole network are presented. These include all of the nodes both interviewed and nominated. Every circle represents an organization, every colour a different type of organization (Figure 14), and the arrow a relationship between two actors (e.g. the existence of an exchange between two actors). The arrow shoots from the organization claiming the tie and points to the organization with which the tie exists. A brief description of the sociograms, or the visualized webs, will accompany each Figure. More in depth discussions follow in the specific findings subsections for each network measure.

Figure 14 Legend of colour for type of node

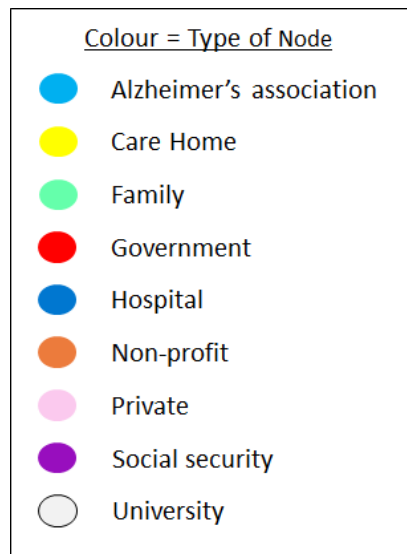
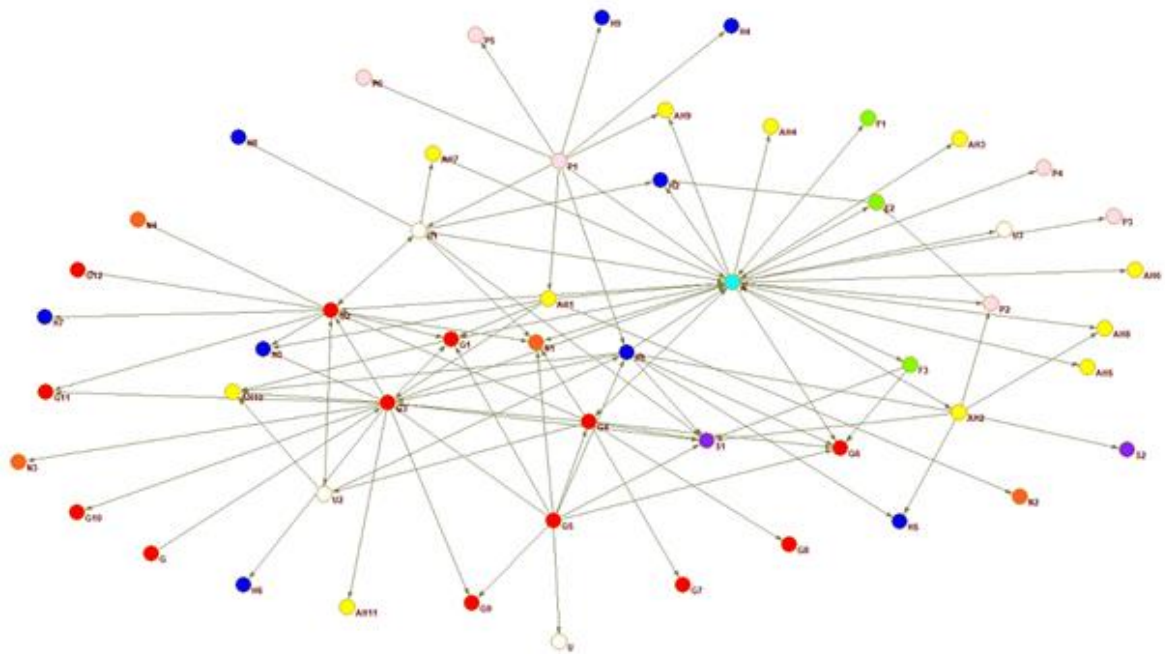


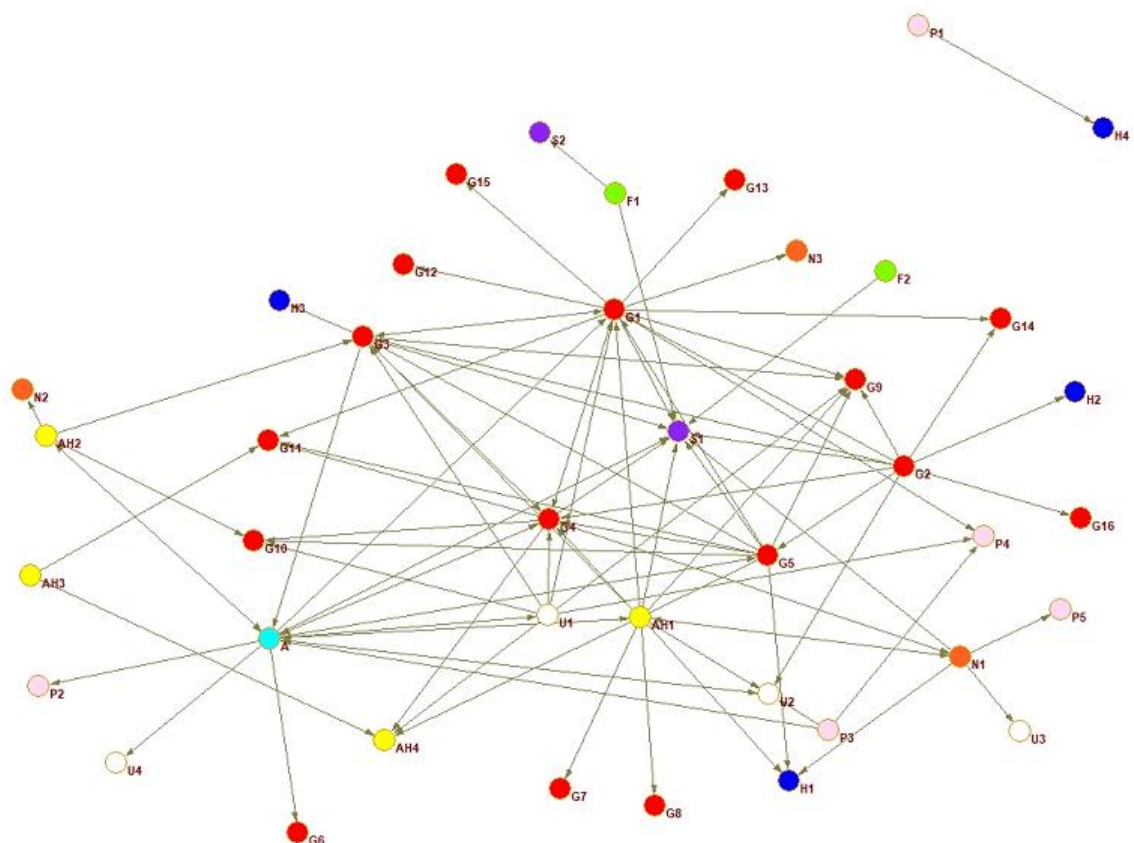
Figure 15 Guatemala: whole network



Guatemala's network included 53 nodes. From Figure 15, the central position of the Alzheimer's association (the turquoise circle) is evident. In addition, the many outermost nodes that have only one tie connecting them to the network are also evident. This reads as a rather centralized network, where a few organizations coordinate interactions. The visual also portrays a grouping of organizations, where on the left side of the web a concentration of the government (red)

organizations is found. On the right side, the care homes (yellow), families (green) and private organizations (pink) are gathered. Sorting such as this occurs as similar organizations are either linked to each other, or linked to the same organizations. Therefore, this sociogram portrays a trend of government organizations to be more in contact with each other than with other types of organizations, while the privates and care homes are ties to the same organizations. The families are not in the centre of the network, and it can be stated that they are not well connected. From the visual, this network appears to be somewhat organized, and that all nodes can receive information or join in collaboration.

Figure 16 El Salvador: whole network

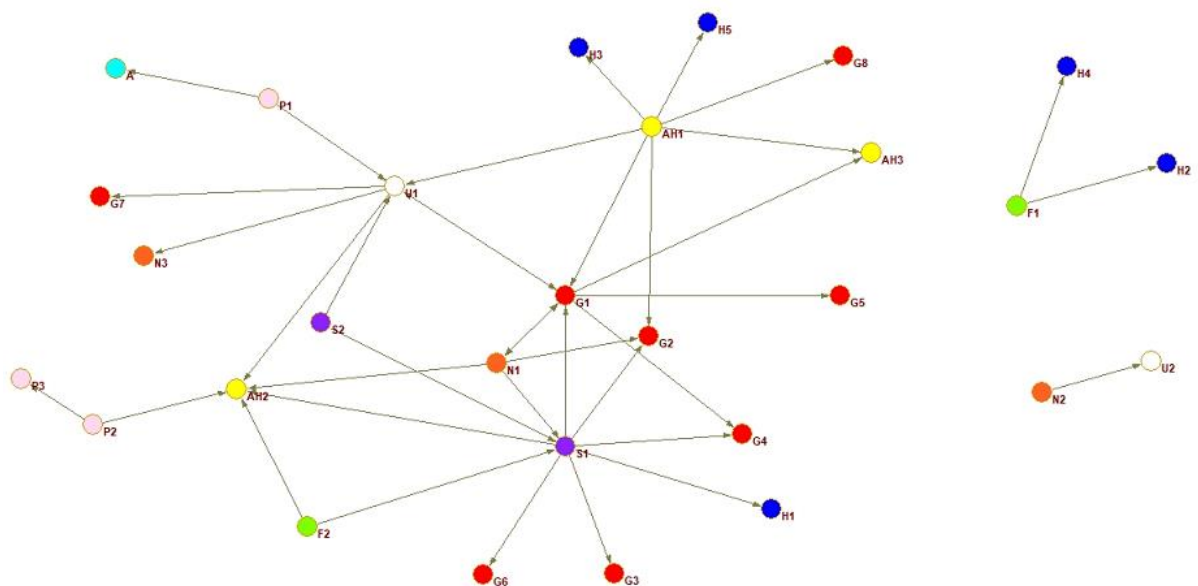


El Salvador's network included 41 nodes. Figure 16 shows a network with a few most central nodes: 1 care home (yellow), 3 government (red), 1 Alzheimer's association (turquoise), and 1 social security (purple) organization. As in Guatemala's network, nodes surround the core of the network with one tie



connecting them to the rest of the organizations. Also similarly, to Guatemala's network, the Alzheimer's association (turquoise) plays a centre role connecting multiple nodes. This was an unexpected result contrasting what emerged from the interviews, where the association offered a dearth of services and was not well known. A separate component, or grouping of nodes, completely disconnected from the main network is found in the upper right hand corner, made up of a private organization and a hospital. The families (green) in this network are also on the outside, barely connected. From this image, the network appears to be chaotic. It would seem an arduous task to get information from one side of the network to the other.

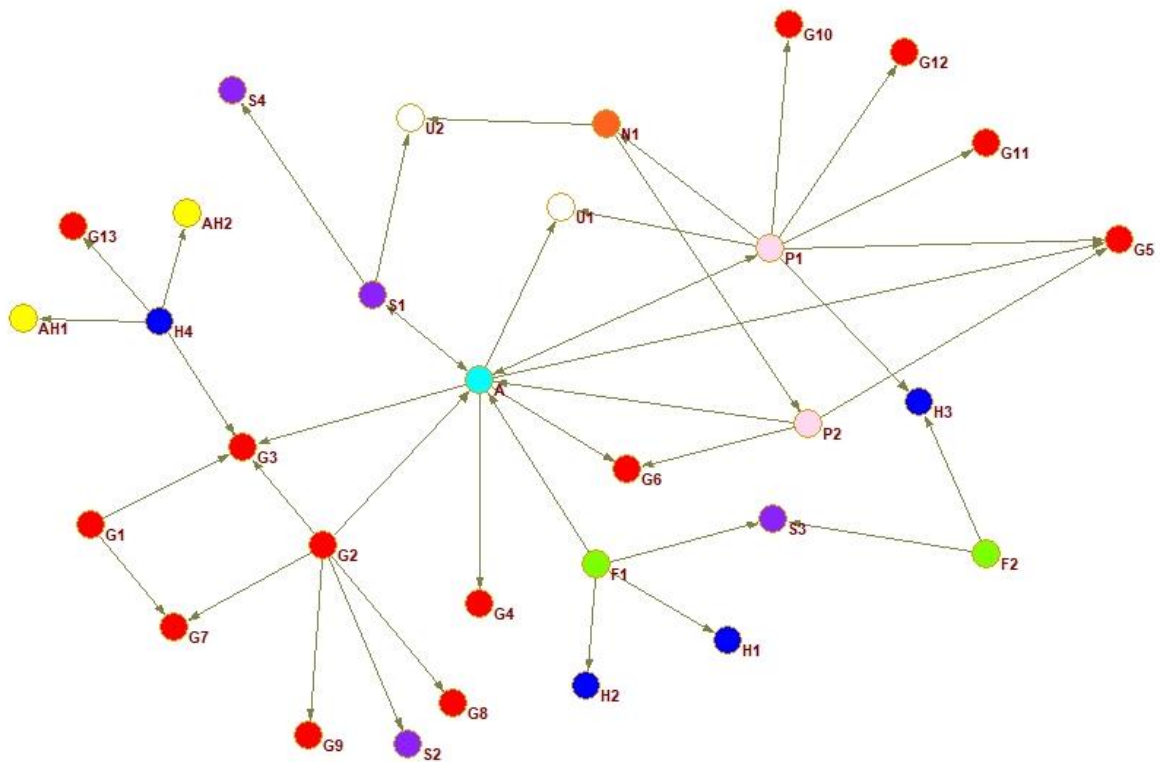
Figure 17 Honduras: whole network



Honduras' network was made up of 29 organizations. Figure 17 depicts a somewhat fragmented network. Two components on the right are not connected to the main network. Yet on the left side of the visual, three groups appear that look like stars with the centres being a university (white), a care home (yellow), and a social security (purple). A government organization (red) interconnects the three main parts of the network, which are not directly interconnected. Exchange could flow quite easily through the main network on the left, where the groups are connected with each other. One of the families (green) is in the totally separated

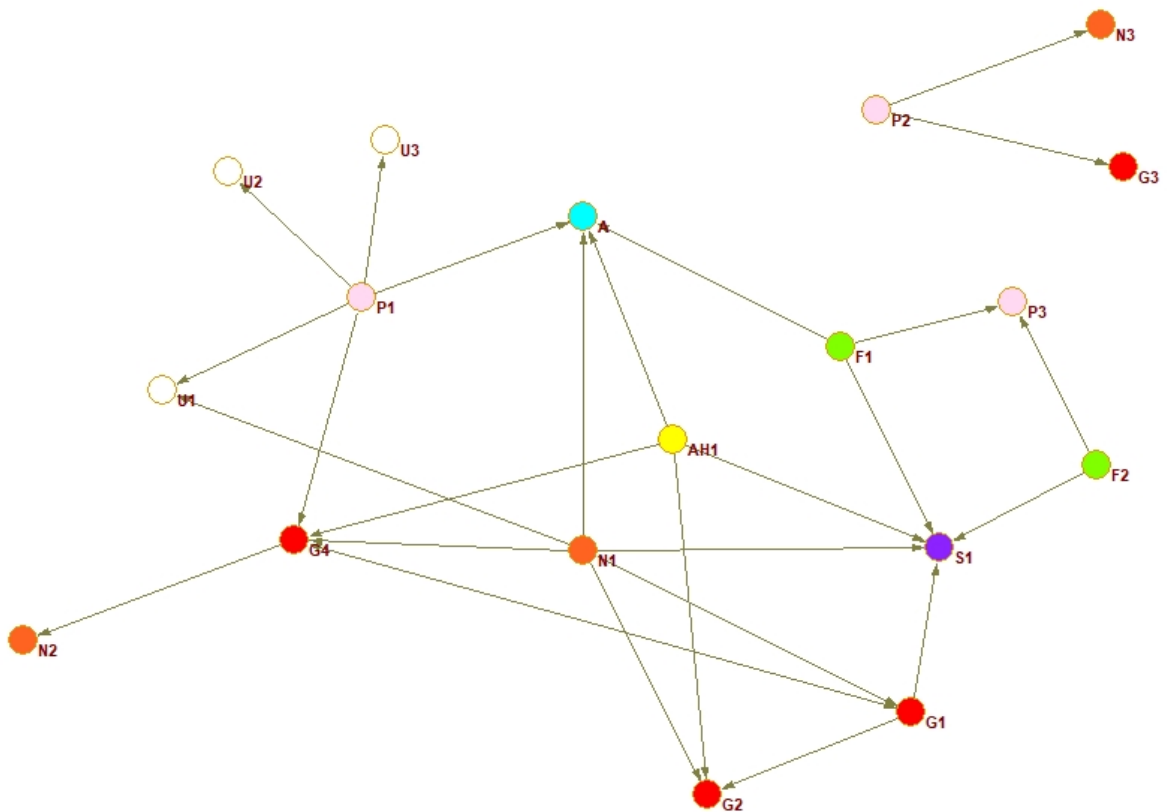
components of the network on the right of the web only connected to two hospitals (blue). This underlines the total disconnect of the family from any other services being offered. The other component is a non-profit and a university who are tied, yet not to the main network.

Figure 18 Costa Rica: whole network



Costa Rica's network includes 31 nodes. This network (Figure 18) is also made up of various groups, where the central nodes are a government (red), the Alzheimer's association (turquoise), and a private (pink). The visual shows government agencies concentrated on both sides of the web, creating what seems like two separate coalitions. Outer nodes have only 1 tie connecting them to the network. Families in this network, have at least 2 connections and 1 in common, which may act as a bridge between them, but evidently did not connect them to each other directly. The ties in this web seem somewhat disorganized, or fragmented. For example to get information to G1 on the left side, from the inner network, would take effort to pass it through at least 2 other organizations.

Figure 19 Panama: whole network



Panama's network included 27 ties. Figure 19 portrays a few central players in this network: a private organization (pink), a government (red), a non-profit (orange), a care home (yellow), the Alzheimer's association (turquoise), and a social security agency (purple). One separate component, a private (pink), a non-profit (orange), and a government agency (red), is disconnected from the rest of the network. Similarly to Costa Rica, the families in this network are tied to the same private and social security organizations, but not to each other.

This general view of the whole networks provides a vivid visual perspective of the organizations involved, and how they are connected. In addition, the sociograms, or webs, offer an impactful glance onto a healthcare system. The participants of the networks rarely acknowledge this macro perspective, especially as hierarchical organizational charts are the norm in visualizing structure. In addition, as stated in the limitations section, networks are fluid, not static, meaning the ties change in time as do the exchanges, making them onerous to keep up with. The following section describes the findings of the density analyses.

## Density

The availability of accessing a variety of actors enables finding “multi-scale solutions to multi-scale problems” (Blanchett and James 2012, p443) such as complex needs from dementia and comorbidities. Density is the measure of the total number of actual ties in a network divided by the total number of possible ties. The number of connections within a network offers insight into the ties organizations have to a variety of other organizations, as opposed to having ties only with previously known organizations or those offering similar services. This access to a variety of organizations denotes the interconnections between disciplines and sectors within a health care system, thus fostering multidisciplinary, the foundation of the biopsychosocial model in dementia care, and a key element of integrated care and system integration.

Density values lie between 0 and 1, where if all possible ties are actualized, the result is 1, and 0 is no ties are actualized at all. Thus, the closer the result is to 1, the higher the density of the network.

Another aspect of the number of connections is the speed of exchange between the organizations. It has been shown that the higher the density or the more connected organizations are to one another, the faster exchanges such as information flow through the network (Blanchet and James, 2013). Valente et al. (2015, p.7) identify a “Goldilocks Principle” where just the right amount of density must be determined where levels below .30 are low; levels .30 to .50 are moderate and appropriate to knowledge sharing and harmony between actors; and density levels above .50 are deemed too high possibly thwarting collectivity and dissemination, or creating a barrier to external exchange (Hoe et al., 2019).

Table 41 displays the density levels of a network by country and rank. Following on the seminal work on interorganisational networks by Provan and Milward (1998, 1995), the networks within each indicator have been ranked in order of highest to lowest density score. The green highlights the highest scores and the blue the

second highest density scores. The cross-country comparisons offer context for the scores amongst other networks. Where a score may seem high, in comparison to other countries' scores of the same indicator network, the score may result as being low.

Overall, the results demonstrate very low density in all networks; barely 10% of possible ties were actualized except in reciprocity. The highest whole network density was of Panama at .083. Within the reciprocity networks, the scores were higher, reaching approximately 20% and 50%, because the respective networks included maximum two ties. This points to generally very low integration levels. The results also portray two countries with consistently higher density in all indicators, El Salvador and Panama, meaning the organizations in these countries are more connected to each other than in the other countries. These results were surprising because based on the interviews, the descriptions provided by the organizations' representatives, depicted networks with a lack of awareness of service providers.

Within each country, with the exclusion of El Salvador, density scores were similar in all of the indicator networks, except reciprocity. The collaborative ties network emerged as the most connected in El Salvador, with almost 10% of all possible ties, where the whole network reached slightly above 5%. This was the biggest difference between networks of one country. The density score of the collaborative ties in El Salvador was also the highest density score for all of the networks analysed. Although this result indicates that the organizations claiming collaborative ties effectively had more ties than those claiming other indicators, the actual density score of ~10% is too low to imply significant integration as per the aforementioned Goldilocks Principle.

Table 42 outlines density scores for the networks of each exchange category and multiplex exchanges by country. Within the most frequent multiplex ties, Costa Rica's network exchanging information+resources+collaboration scored the highest density of all exchange categories, having 12% of possible ties. In addition, the information+resources network also scored the highest density, as did Guatemala's network of ties exchanging resources+collaboration. Again,

basing an evaluation of the scores on the abovementioned “Goldilocks Principle” (Valente et al. 2015), the density scores are very low indicating very low integration. The surprising results are that in general the highest scores are in the multiplex tie IRC, except for in Guatemala. Being the largest network could make connecting more difficult, but considering the interview descriptions, it seemed to be the most interconnected.

In the exchange of information, resources and collaboration, Panama has the most connected networks. This could be due to Panama having the smallest general network. Honduras also has the highest density score in the exchange of collaboration. Nevertheless, only approximately 10% of possible ties are realized between the organizations, which again indicates very low integration scores.

In this section, the analyses findings for the integration indicator density were outlined. Based on the density scores described, the conclusion is that integration is very low in the Central American older adult service networks. Organizations are not connected, creating a barrier to providing integrated care to older adults, especially with dementia.

Table 41 Network density by integration indicator and country

COUNTRY	Guatemala			El Salvador			Honduras			Costa Rica			Panama		
Indicators	N =	Score	Rank	N =	Score	Rank	N =	Score	Rank	N =	Score	Rank	N =	Score	Rank
WHOLE NETWORK	53	.039	5	41	.056	2	29	.045	3	31	.043	4	27	.083	1
TYPE OF TIE Collaborative	32	.043	5	24	.089	1	17	.048	4	17	.055	3	11	.074	2
STRENGTH 7-10 importance	35	.038	5	32	.058	2	21	.045	3	25	.043	4	11	.083	1
RECIPROCITY	13	.142	4	7	.286	3	3	.444	2	3	.444	2	2	.5	1
DEMENTIA SPECIFIC	45	.039	5	27	.073	1	27	.046	4	21	.057	3	16	.07	2

N=total number of nodes

Table 42 Network density by exchange network

COUNTRY	Guatemala			El Salvador			Honduras			Costa Rica			Panama		
Indicators	N =	Score	Rank	N =	Score	Rank	N =	Score	Rank	N =	Score	Rank	N =	Score	Rank
IRC	20	.043	5	16	.07	4	5	.12	2	7	.122	1	8	.11	3
RC	12	.083	1	23	.045	5	12	.063	2	13	.047	4	9	.062	3
IR	26	.041	5	14	.046	3	8	.063	2	6	.083	1	0		
Info	45	.036	5	30	.048	3	19	.044	4	16	.055	2	9	.11	1
Referrals	24	.049	4	21	.052	3	10	.07	1	12	.063	2	8	.063	2
Resources	50	.038	5	39	.053	2	24	.047	3	27	.044	4	18	.062	1
Collaboration	29	.049	4	31	.061	2	16	.066	1	23	.042	3	16	.066	1

I=information; R=resources; C=collaboration; N=total number of nodes

## Closeness Centrality

Centrality is a fundamental indicator of integration in that it is related to how groups organize to find solutions to shared problems (Freeman, 1978). De Nooy and Bataglj (2005) use the concept of centrality in networks based on Freeman's (1979) work. Three main ideas frame the perspective that being central means: "(1) being active within the network, that is, maintaining many ties, (2) being efficient or independent of go-betweens by having short distances to other [organizations] in the network, and (3) being an important go between, that is, being part of many paths between other [organizations] in the network" (ibid, p.10). The centralization of the relationships between the organizations presents an indicator of the level of managed coordination (Morrissey et al. 1985), and managed coordination is encompassed as one of the elements of integration and integrated care (Leutz 1979). Additionally, in a systematic review by Suter et al. (2009) leading to 10 consistent principles for successful integration, promoting coordination was a subheading of the principle governance structure.

Measuring network closeness centrality provides an indication of how close nodes are to each other and thus their ability to pass on information or resources to others in the network. Where organizations in the network have short paths to other organizations, the network has high closeness centrality. For example, if A is directly connected to C it is a shorter path than if A is connected to B who is then connected to C. In the latter case, A has an indirect tie to C via B, resulting in lower closeness centrality. Centrality scores ranges from 0 to 1, where high scores, closest to 1, signify a highly centralized network with few nodes that connect all of the other nodes. Hossain (2009) argues that high network centrality is associated with greater coordination of the network, and vice versa. Coordination is linked to integration, as one of the core principles of integrated care leading to a continuum of care (Suter et al., 2009). Therefore, high closeness centrality scores are an indicator of high levels of integration.



Closeness centrality of each node was also measured. This analysis provides a view of the most central node in each network. The organization with the shortest path, or closest to every other organization in the network, will have the highest closeness centrality score. Node closeness centrality scores also range from 0 to 1, where 1 indicates that a node is connected directly to all other nodes.

In this section, network closeness centrality of the networks is compared between countries and within countries, and associations to node closeness centrality are explored. The between country comparisons offer context for the scores amongst other networks. Where a score may seem high, in comparison to other countries' scores of the same indicator network, the score may result as low.

Tables 43 and 44 show network closeness centrality scores by indicator and country. Where an asterisk is present, more than two components were present in the network. This means that within that particular network, there were more than two groups of nodes separated from each other. Scores were thus calculated on the largest group of nodes in the network. In three cases, the components were multiple and made up of only two nodes, therefore centrality scores were incalculable and left blank.

As in the density tables, scores have been ranked from 1, for the highest closeness centrality score, to 5 for the lowest within the indicator among countries. The reciprocity networks of Honduras, Costa Rica and Panama were made up of 3 and 2 organizations, facilitating higher closeness centrality scores.

The most centralized networks emerged from Guatemala and Costa Rica. All of the networks in Costa Rica resulted as highly centralized, with the high strength network having more than two components thus having pseudo high centrality. This finding was very surprising, contradicting the sense of siloes emerging from the interviews. This dissonance could confirm an underlying influence within the network that participants may not be aware of or may not want to acknowledge openly. The high network closeness centrality scores in fact confirm that there are key organizations within the network that are well connected, and thus may have influence over who exchanges what. Further confirmation is given by the

exchange categories' closeness centrality scores (Table 43). Three of the four exchange networks that scored high closeness centrality in Costa Rica were in actuality made up of two or more components, signifying they were fragmented. The high scores were of the largest components. Nevertheless, the central organizations in the networks (Tables 44, 45) maintained their central positions within the specific categories of exchange. These findings confirming a status of influence and power, which could also be construed as control, are more easily understood through the visualizations provided in Figure 20.

Tables 44 and 45 further confirm the static position of one of the organizations, the Alzheimer's association, showing it as the node with the highest closeness centrality throughout all of the networks in both countries.

Table 43 N Network closeness centrality by integration indicator

COUNTRY	Guatemala			El Salvador			Honduras			Costa Rica			Panama		
	network	Nodes	Score	Rank	Nodes	Score	Rank	Nodes	Score	Rank	Nodes	Score	Rank	Nodes	Score
WHOLE NETWORK	53	.524	1	41	.386	3	29	.305	4	31	.456	2	27	.267	5
TYPE OF TIE Collaborative	32	.349	4	24	.333	5	17	.424*	3	17	.575	2	11	.635*	1
STRENGTH total 7-10	35	.395	2	32	.313	4	21	.3*	3	25	.526*	1	11	.313	4
RECIPROCITY	13	.504	3	7	.527	2	3	1	1	3	1	1	2		
DEMENTIA SPECIFIC	45	.6	1	27	.404	3	27	.391	4	21	.454	2	16	.228	5

\* more than 2 components

Table 44 Network closeness centrality by exchange network

COUNTRY	Guatemala			El Salvador			Honduras			Costa Rica			Panama		
	network	Nodes	Score	Rank	Nodes	Score	Rank	Nodes	Score	Rank	Nodes	Score	Rank	Nodes	Score
IRC	20	.536*	5	16	.662*	2	5	1	1	7	.637	3	8	.556	4
RC	12	.272	5	23	.319*	3	12	.283*	4	13	.422*	2	9	1*	1
IR	26	.492*	2	14	1*	1	8	8		6	3		0		3
Info	45	.444	3	30	.325*	3	19	.441*	4	16	.537*	1	9	0.49	2
Referrals	24	.502	2	21	.364*	4	10	1*	1	12	.422*	3	8	4 com	
Resources	50	.462	1	39	.392	3	24	.381*	4	27	.423	2	18	.294	5
Collaboration	29	.377	3	31	.36	5	16	.381*	2	23	.424*	1	16	.363	4

\* more than 2 components

Table 45 Closeness centrality and type of node by integration indicator

COUNTRY	Guatemala			El Salvador			Honduras			Costa Rica			Panama		
	network	N =	Score	Type	N =	Score	Type	N =	Score	Type	N =	Score	Type	N =	Score
WHOLE	53	.658	A	41	.55	A	29	.489	AH	31	.556	A	27	.5	AH
TYPE OF TIE	32	.518	A	24	.575	G	17	.636	AH	17	.667	A	11	.8	G
STRENGTH total	35	.531	A	32	.534	A	21	.56	S	25	.62	A	11	.538	G/P
RECIPROCITY	13	.632	A	7	.75	A	3	1	G	3	1	A	2		
DEMENTIA	45	.71	A	27	.632	AH	27	.561	G/AH	21	.571	A	16	.522	A

*N = total number of nodes in network*

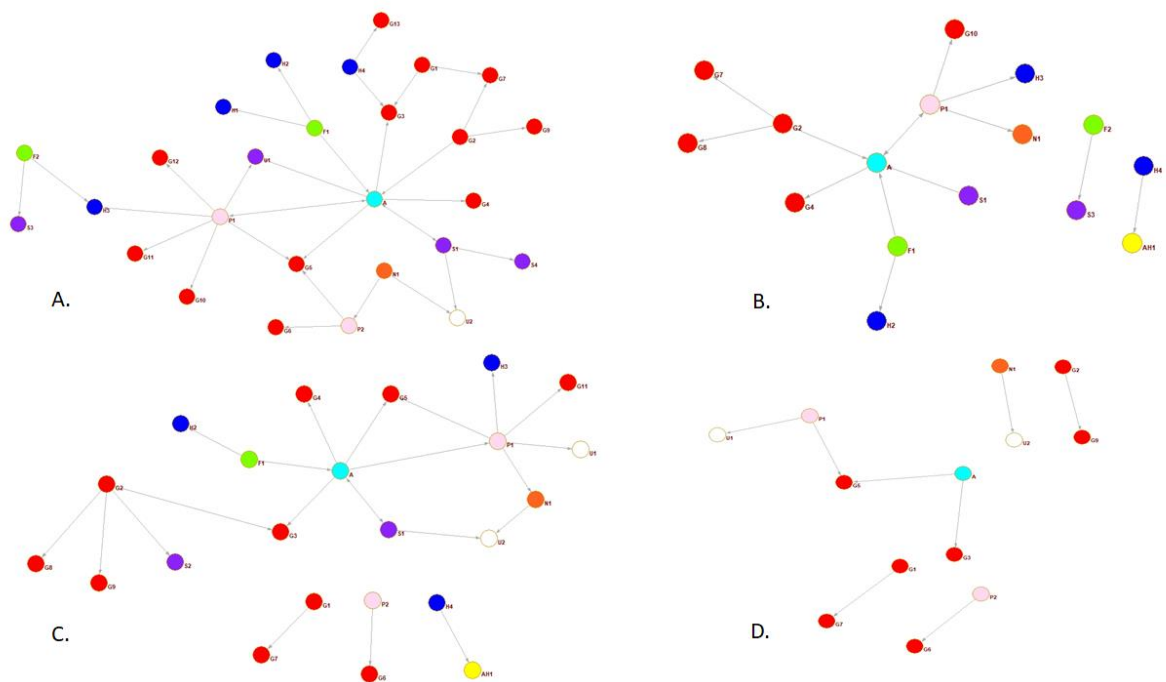
Table 46 Closeness centrality and type of node by exchange network

COUNTRY	Guatemala			El Salvador			Honduras			Costa Rica			Panama		
	network	N =	Score	Type	N =	Score	Type	N =	Score	Type	N =	Score	Type	N =	Score
IRC	20	.65	G	16	.786	G	5	1	S	7	.75	A	8	.714	P
RC	12	.474	G/U	23	.455	G	12	.5	G/AH	13	.571	A/P	9	1*	G
IR	26	.588	A	14	1*	AH	8	1*	8	6	1*	3	0		
Info	45	.587	A	30	.535	G	19	.4	AH	16	.647	A	9	.615	P
Referrals	24	.639	A	21	.5	G	10	1*	S	12	.667	A	8	*	4 com
Resources	50	.613	A	39	.59	G	24	.563	U	27	.52	A	18	.467	G
Collaboration	29	.55	G	31	.545	G	16	.611	G	23	.552	A	16	.625	P

*N = total number of nodes in network; \* more than 2 components*

Costa Rica is the only country with this pattern of closeness centrality throughout its various networks. Even in the low ranking networks of exchange categories (Table 44), although lower than other countries' scores, the centrality maintains .4 and above (closest to 1).

Figure 20 Costa Rica exchange networks:  
 A: Resources B: Information; C: Collaboration, D: Resources+Collaboration

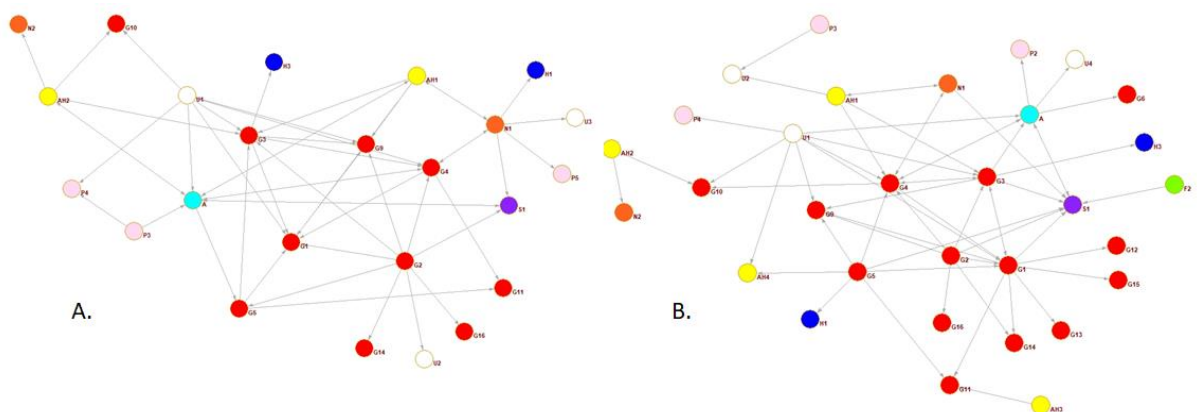


In Guatemala, the highest-ranking centrality scores were notable in the whole network, the dementia specific network and the resources network. In the visualization of the strength network, and the resource exchange ties networks, the most central nodes are noticeable. A low centrality network such as the RC, resources and collaboration exchange ties network, is instead visually fragmented (Figures 21, 22)



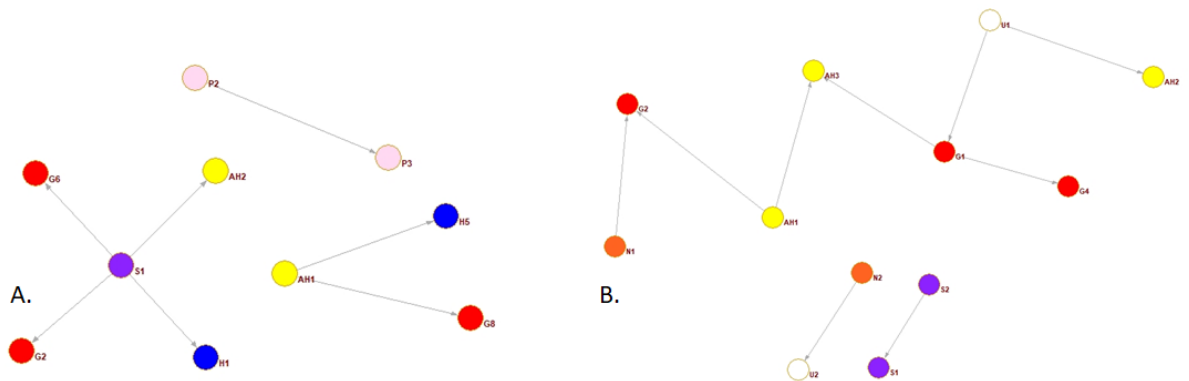
El Salvador's networks rank generally low in centrality and the exchange category networks are mostly fragmented made up of two or more components. Figure 23 shows the networks ranking the lowest in closeness centrality: the collaborative ties and the collaboration exchange ties. Both networks show unclear central positions. These visuals and the centrality scores match interview descriptions and the ambience captured during the fieldwork. A chaotic and confused set of organizations, desiring cooperation yet needing coordination. The overwhelming presence of government organizations (red) is evident in the visualizations, and in the high node centrality scores.

Figure 23 El Salvador: A. Collaborative ties, B. Collaboration exchange



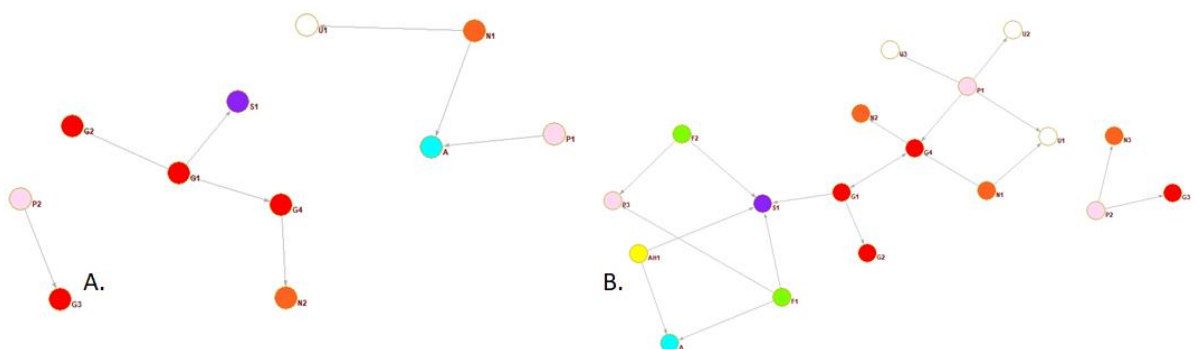
The majority of Honduras' networks were fragmented, made up of two or more components. In the referrals network, the largest component had a closeness centrality score of 1 because one organization referred directly to the other organizations (Figure 24), while the lowest closeness centrality score in the country resulted in the multiplex resources + collaboration exchange ties network. Through the visualization of the networks, the fragmentation is obvious. The lack of centralization, thus coordination, is further confirmed in the node centrality scores, where there is a lack of consistency of central nodes.

Figure 24 Honduras: A. Referrals exchange, B. Resources and collaboration exchange



For Panama, closeness centrality scores were generally low, except where there were two or more components. For example, the highest-ranking network, the collaborative type of tie is shown in Figure 25 together with the lowest ranking exchange category network, resources. The fragmentation is clear in both networks, though in the collaborative ties a central organization does exist in the largest component, which has three ties. Whereas in the resource exchange network, the organizations are more connected as a string, having one or two ties, making any sharing cumbersome, taking many steps to get from one end of the network to the other. As in Honduras, the low network centrality scores are confirmed in the highest node centrality, where no one organization has a consistent central position, making coordination and collaboration difficult.

Figure 25 Panama: A. Collaborative type of tie, B. Resources exchange





The differences between density and closeness centrality within networks highlight how the number of ties is not correlated to coordination. For example, the networks of both Guatemala and Costa Rica have low-density rankings in the cross-country comparisons. In the same comparisons, their centrality scores rank highest and the same organization results as the most central in both countries' networks: the Alzheimer's association. These findings indicate that Guatemala and Costa Rica's older adult networks have a more centralized structure, which theoretically enables coordination, exchange, and collaboration. This potential for facilitated exchange is confirmed in the high-ranking centrality scores of the individual exchange category networks in both Guatemala and Costa Rica.

An opposite scenario emerges in El Salvador and Panama. Density scores are ranked highest in these countries' integration indicator networks, while for the most part, lowest in the closeness centrality scores, with inconsistency in the node type with the highest centrality. The exchange category networks do not capture the same pattern, resulting in incongruent findings. These incongruences depict disorganized networks, perhaps shaped by sporadic needs based relations.

In this section, the findings for the integration indicator closeness centrality were described. Guatemala and Costa Rica resulted as having the highest centrality scores, indicating organizations are close to each other, or have many ties, which allows them to pass on information or resources to others in the network. In addition, one organization had a consistent central position in most of these countries' networks, reinforcing the probability of coordination and collaboration. Closeness centrality is an indicator of coordination according to Morrissey et al. (1985), which is an element of integration. Thus, it follows that integration is high in Guatemala and Costa Rica, for this integration indicator. The remaining countries resulted as having networks with low closeness centrality, leading to a conclusion of low integration.

## E - I Index

Reiterating Blanchett and James (2012), connections across organizations lead to multidisciplinary approaches to complex needs, resulting in an integrated care approach. The E-I index measure addresses the wide range of care interventions required in an integrated approach to care (Nicaise et al. 2013). Assessing the predominance of ties between organizations of the same type, or between organizations of different types is an additional indicator for a network's level of fragmentation or integration. Adapting Krackhardt and Stern's (1988) assumption about individuals, organizations dedicate time and resources to foster connections and collaborations with other organizations. Both are limited, consequently limiting the number of active connections. Thus, as previously described by the exchange perspective in organizational theory, organizations base ties on opportunity and on benefit/cost analysis (Provan and Milward 1995). Accordingly, the more internal ties an organization has, the less capacity it will have for more ties that are external.

The external - internal index was advanced by Krackhardt and Stern's (1988) as a measure of within ties and between ties. The number of ties external to the group is subtracted by the number of ties that are internal to the group and divided by the total number of ties (Hanneman & Riddle, 2005). The value can range from 1 to -1. The groups, in the networks of this study, are the categories of types of organizations. Therefore, the E-I index of a country's network would be the calculation of: the number of ties that each organization has with other types of organizations, (e.g. a care home with a family), minus the number of ties that each organization has with an organization of the same type, (e.g. a care home with another care home), divided by the total number of ties in the network. The number of groups that exist in a network, the number of ties within each group, and the number of ties in general in the network affects the range of possible external to internal index values. The software UCINET (Borgatti et al. 2002), re-scales the parameter to range between the maximum possible degree of external ties (+1) and the maximum possible degree of internal ties (Hanneman & Riddle, 2005). The resulting score ranges from -1 where all of the ties are internal to a

group, to +1 where all ties are external to the group. A higher score indicates greater diversity of relations between groups, implying multi-disciplinarity and multi-sectoriality, which indicates a higher level of integration.

Table 47 E-I index scores by integration indicator

COUNTRY	Guatemala		El Salvador		Honduras		Costa Rica		Panama		
	N =	Score	N =	Score	N =	Score	N =	Score	N =	Score	
WHOLE NETWORK	53	.535	41	.357	29	.676	31	.6	27	.647	
TYPE OF TIE	32	.571	24	.373	17	.722	17	.641	11	.75	
STRENGTH total 7-10	35	.524	32	.418	21	.7	25	.667	11	.333	
RECIPROCITY	13	.667	7	0	3	1	3	1	2	1	
DEMENTIA SPECIFIC	45	.699	27	.907	27	.688	21	1	16	1	
	≥ .7	≤ .3	<i>I=information; R=resources; C=collaboration; N=total number of nodes</i>								

Table 48 E-I index scores by exchange network

COUNTRY	Guatemala		El Salvador		Honduras		Costa Rica		Panama		
	N =	Score	N =	Score	N =	Score	N =	Score	N =	Score	
I+R+C	20	.176	16	.412	5	1	7	1	8	0	
R+C	12	.4	23	.167	12	.333	13	.5	9	1	
I+R	26	.538	14	.556	8	.722	6	1	0	-	
Information	45	.536	30	.333	19	.875	16	.692	9	0	
Referrals	24	.857	21	.364	10	.667	12	.5	8	.5	
Resources	50	.558	39	.36	24	.615	27	.667	18	.75	
Collaboration	29	.316	31	.208	16	.5	23	.619	16	.75	
	≥ .7	≤ .3	<i>I=information; R=resources; C=collaboration; N=total number of nodes</i>								

Tables 47 and 48 show that the majority of the networks are closer to having more external ties than internal ties, with E-I index scores between .3 and .7. Negative results were not found. The lowest index finding, zero, indicates three networks with equal internal and external ties. Low index measures, relative to the findings, are highlighted in pink and are closest to zero. These findings provide a context of baseline diversity within the networks, indicating an underpinning of integration. The highest score, 1, indicating a network where all organizations have no ties with their same type of organization, was found in 9 networks. This finding is most interesting in the larger of these networks, the dementia specific networks of Costa Rica and Panama, because of two possibilities: the more organizations present in a network, the more likely a tie with the same type of organization will occur; or, the network has few ties which decreases the likelihood of the same type of organizations being connected. Both of these networks had the highest density

measures within the dementia specific network category (Table 41). Therefore, the networks with only external ties also had the most ties.

Purple highlighted index measures, equal to or above .7, indicate networks where 70% or more of the ties are external, further indicating highly diverse networks. Honduras and Panama result having the most highly diverse networks, where the networks of the other countries appear to maintain a part of their ties to same type organizations.

This section illustrated the analyses findings for the E-I index integration indicator. Generally, results were between .3 and .7 indicating moderate levels of external ties. Two countries resulted having mostly external ties in at least half of their networks. These findings sustain that environments with a range of connections, multi-disciplinary and multi-sectoral, allow organizations to meet complex needs as put forward by the integration literature (Bunn et al. 2017, Browne et al. 2007, Nicaise et al. 2013, Fox et al. 2013, Provan and Milward 1995).

## QAP Correlation

Quadratic assignment procedure (QAP) is a method of testing social network data for statistical significance (Barnett, 2011). "This procedure is principally used to test the association between networks" (Hanneman & Riddle, 2005). In essence, QAP correlation tests to understand when a tie exists between two organizations in one network, if it is likely that those same organizations will be tied in another network. Similarly, if two organizations exchange resources, are they also likely to exchange something else. QAP correlation testing is completed in order to understand if the same ties are likely to reoccur, or not, in different networks. This measure tests the association between networks.

Maintaining that statistical significance is the likelihood that a relationship between two (or more) variables is caused by something other than chance, statistically significant QAP scores are shown in Tables 48-52.

A low probability, where statistical significance is lower than 5% ( $p < 0.05$ ), suggests a strong relationship between the networks that is unlikely to have occurred by chance. According to Hanneman & Riddle (2005), ties that interact in one type of exchange are more likely to interact in another exchange. Yet another possibility is where no correlation is present, indicating an exchange between those two organizations occurs only in one network.

Table 47 QAP correlation scores by network: Guatemala

GUATEMALA	1	2	3	4	5	6	7	8	9	10
1 collaboration										
2 collaborative tie	0.587									
3 dementia	0.392	0.831								
4 information	0.446	0.797	0.703							
5 I+R	-0.012	0.497	0.416	0.614						
6 I+R+C	0.641	0.386	0.236	0.478	-0.008					
7 R+C	0.538	0.324	0.22	-0.011	-0.007	-0.005				
8 referral	0.107**	0.497	0.503	0.479	-0.01	-0.008	-0.007			
9 resources	0.519	0.927	0.79	0.762	0.536	0.417	0.35	0.457		
10 strength	0.354	0.646	0.548	0.554	0.462	0.312	0.162***	0.182	0.636	
11 reciprocity	0.083*	0.212	0.187**	0.126**	0.158**	-0.005	0.163**	0.048	0.169**	0.204***

\* $p < .05$ , \*\*  $p < .01$ , \*\*\* $p < .001$

In Guatemala (Table 48), QAP scores indicate that organizations that share reciprocal ties also perceive their ties as strength ties (row 11, column 10, 0.204) and the organizations that reciprocate tend to be dementia specific (row 11, column 3, 0.187). These reciprocal ties exchange collaboration (row 11, column 1, 0.083), information (row 11, column 4, 0.126), resources (row 11, column 9, 0.169) and are likely multiplex ties exchanging both information and resources (row 11, column 5, 0.158), or resources and collaboration (row 11, column 7, 0.163). Additionally, strength ties are highly likely to engage in multiplex exchanges of resources and collaboration (row 10, column 7, 0.162) and ties that exchange referrals are likely to exchange collaboration (row 8, column 1, 0.107). In sum, the picture portrayed by the QAP correlation is that in the Guatemalan system, reciprocity correlates with other types of ties and types of exchange, where other attributes do not.

This is an expected finding, which is biased. Reciprocity, in this study, was an all-inclusive measure, as described in chapter 6. A tie was considered reciprocal when both organizations claimed a relation to each other. Reciprocity was not based solely on any specific type of attribute or exchange. Therefore, the network of reciprocal ties is likely correlated with any other network in which the same ties are found. To clarify further, an example in Guatemala is a government organization and a university both claim having a tie to each other. Thus, this is considered a reciprocal tie. The government organization claims to exchange collaboration with the university, while the university claims to exchange resources with the government organization. Accordingly, the reciprocity network is correlated to the collaboration network and the resources network, because it is highly likely that more than chance causes the same organizations to be tied in three different networks. In fact, the bias of the finding is that the reciprocity network will result correlated to all of the networks to which the reciprocal ties pertain.

The findings also indicate that although organizations exchange something, an assumption cannot be made that they also exchange other things. Most networks are not correlated to each other. What seems to emerge from Guatemala's system, is that exchange between organizations is based on what they have available and what they need. In countries where economic funding is scarce, as are public resources in general, the subtext of the interviews depicted the same scenario of exchange based on available surplus.

In El Salvador (Table 49), strength ties were likely to be claimed as collaborative ties (row 11, column 2, 0.078) and engage in multiplex exchanges of information, resources, collaboration (row 11, column 6, 0.086); and resources, collaboration (row 11, column 7, 0.102). Additionally strength ties are likely to exchange referrals (row 11, column 9, 0.087) and resources (row 11, column 10, 0.095). This finding implies that in this country, the strength of a tie is associated with interacting and exchanging.

Table 48 QAP correlation scores by network: El Salvador

EL SALVADOR	1	2	3	4	5	6	7	8	9	10
1 collaboration										
2 collaborative tie	0.788									
3 dementia	0.604	0.67								
4 information	-0.014	0.303	0.453							
5 I+R	0.546	0.43	0.642	-0.007						
6 I+R+C	0.631	0.498	-0.019	-0.009	-0.012					
7 R+C	0.088*	0.146**	0.048	-0.005	0.083	0.07				
8 reciprocity	0.367	0.487	0.468	-0.008	-0.012	-0.014	-0.007			
9 referral	0.712	0.93	0.615	0.326	0.463	0.535	0.158**	0.38		
10 resources	0.631	0.774	0.584	0.296	0.42	0.386	0.138**	0.284	0.742	
11 strength	0.044	0.078*	0.013	0.057	-0.01	0.086*	0.102*	-0.012	0.087*	0.095*

\*p < .05, \*\* p < .01, \*\*\*p < .001

Neither having a reciprocal tie nor a dementia specific tie leads to a probability of exchange, and exchanging collaboration or information also does not promote further exchange. These results reiterate the aforementioned culture of exchange based on possession, and highlight the relevance of the strength of a tie. Although the existence of a causal relation between strength and exchange remains unknown.

Table 49 QAP correlation scores by network: Honduras

HONDURAS	1	2	3	4	5	6	7	8	9	10
1 collaboration										
2 collaborative tie	0.014									
3 dementia	-0.024	0.607								
4 information	-0.017	0.642	0.467							
5 I+R	-0.008*	0.319	0.254	0.497						
6 I+R+C	-0.007	0.276***	0.297***	0.43	-0.004					
7 R+C	0.069	0.479	0.219	-0.012	-0.006	-0.005				
8 referral	-0.011	0.422	0.119*	0.563	-0.005	-0.005	-0.008			
9 resources	0.073	-0.001	0.038	-0.021	-0.011	-0.009	-0.016	-0.014		
10 strength	0.036	0.719	0.373	0.551	0.104	0.253**	0.364	0.502	-0.024	
11 reciprocity	-0.006	0.225**	0.242**	0.351**	0.352**	0.407**	-0.004	-0.004	-0.008	-0.006

\*p < .05, \*\* p < .01, \*\*\*p < .001

In Honduras (Table 50), QAP correlation scores portrayed findings similar to those of Guatemala. The reciprocity network was correlated to ties claimed as collaborative (row 11, column 2, 0.225) and dementia specific (row 11, column 3, 0.242), and were likely to exchange information (row 11, column 4, 0.351), and multiplex exchanges of information, resources (row 11, column 5, 0.352), and

information, resources, collaboration (row 11, column 6, 0.407). For the reasons stated previously, these findings are biased.

Strength ties were correlated with multiplex ties exchanging information, resources, collaboration (row 10, column 6, 0.253), indicating that exchanging many things influences the strength of a tie or vice versa. An interesting finding, referrals were correlated with dementia specific ties (row 8, column 3, 0.119), would imply that dementia specific organizations are likely to refer to each other. This is described and visualized in the next section of this chapter, Dementia Specific Networks, where indeed some of the dementia specific ties appear in the referral network. In line with the interviews, families do not participate in the referral network, and thus do not receive the benefit of this correlation. These QAP correlation findings demonstrating the majority of the networks are not correlated reveal that in Honduras as well, one kind of interaction does not suggest another kind of interaction.

Table 50 QAP correlation scores by network: Costa Rica

<b>COSTA RICA</b>	1	2	3	4	5	6	7	8	9	10
1 collaboration										
2 collaborative tie	0.726									
3 dementia	0.458	0.55								
4 information	0.505	0.577	0.309							
5 I+R	-0.007	0.266	0.109	0.461						
6 I+R+C	0.518	0.376	0.403	0.652	-0.004					
7 R+C	0.599	0.435	0.274	-0.01	-0.004	-0.006				
8 referral	0.42	0.462	0.122*	0.35	-0.005	-0.007	-0.008			
9 resources	0.632	0.88	0.518	0.511	0.302	0.428	0.495	0.285		
10 strength	0.675	0.775	0.468	0.636	0.343	0.32	0.418	0.46	0.736	
11 reciprocity	0.146*	0.104	0.137*	0.186*	-0.002	0.287*	-0.004	-0.004	0.12*	-0.006

\*p < .05, \*\* p < .01, \*\*\*p < .001

In Costa Rica (Table 51), again, a similar scenario is found. The QAP correlation scores show only one correlation outside of the reciprocity networks. As found in Honduras, ties exchanging referrals were correlated with being dementia specific (row 8, column 3, 0.122), with families not benefiting of the correlation as will be described in the next section.



The same conclusion applies to Costa Rica; exchange is based on what is possessed and what is needed. Because organizations engage in one type of exchange, assumptions cannot be made that the same organizations will engage in other types of exchange.

Table 51 QAP correlation scores by network: Panama

PANAMA	1	2	3	4	5	6	7	8	9	10
1 collaboration										
2 collaborative tie	0.781									
3 dementia	0.428	0.659								
4 information	0.719	0.562	0.37							
5 I+R										
6 I+R+C	0.632	0.494	0.336	0.879						
7 R+C	0.533	0.416	0.189*	-0.02		-0.018				
8 reciprocity	0.237	0.185	-0.013	-0.009		-0.008	-0.007			
9 referral	0.351***	0.372	0.34	0.322**		-0.016	-0.013	-0.006		
10 resources	0.746	0.851	0.611	0.582		0.58	0.489	-0.013	0.321***	
11 strength	0.599	0.593	0.425	0.622		0.465	0.268**	-0.009	0.465***	0.548

\*p < .05, \*\* p < .01, \*\*\*p < .001  
 I+R network has no ties, thus was excluded from analysis

Panama (Table 52) results as unique in the QAP correlation analysis, where referral ties appear highly correlated to other networks. Resource exchange and strength ties are correlated to referrals (rows 10/11, column 9, 0.321/0.465) indicating that exchanging resources may influence making referrals or vice versa, and comparably, referrals made could strengthen ties or vice versa. Yet referral ties are also correlated to the exchange of collaboration and information (row 9, columns 1/4, 0.351, 0.322). Therefore, in Panama's networks, making referrals to other organizations is linked to having another type of exchange with those organizations. These findings allow us to assume that if an exchange occurs, the probability of a referral is high. Those networks that are not correlated, the majority in this country as well, illustrate that exchange is not based on exchange. More specifically, the findings demonstrate that exchange does not lead to further exchange between the same two organizations.

This section outlined the QAP correlation analyses completed to understand if networks of tie attributes are correlated with each other. The general findings of all five countries show that having one type of tie does not suggest that the same

organizations will also have another type of tie. Strength and referral networks emerged as correlating with each other and/or the exchange of resources, information and/or collaboration except in Costa Rica. An assumption could thus be made that strong ties also make referrals to each other, and have a high probability of also exchanging something.

Exchange does not lead to exchange, this remains the key finding. Organizations interact for specific exchanges, reinforcing the need to maintain multiple different ties in order to satisfy needs. A one-stop shop culture, where interacting with only one organization fulfils provision needs, evidently is not viable. Based on the context, a general lack of resources imposes a trade market of tangible and intangible goods and services, which underlines the exchange perspective, mentioned in the E-I index section, that organizations base ties on opportunity and on benefit/cost analysis. In turn, this leads to multiple interactions, which could translate to inter-disciplinary and inter-sectoral ties. As previously cited, the availability of accessing a variety of actors enables finding “multi-scale solutions to multi-scale problems” such as complex needs from dementia and comorbidities (Blanchett and James 2012, p443). A variety of ties is the foundation of integration. This is discussed in depth in the final discussion chapter.

The following section is the final section of the chapter, and portrays the consolidated findings for the dementia specific networks.

## Dementia Specific Networks

This study explores the integration of service systems for people living with dementia, thus it is essential to view independently the integration indicator findings of the dementia specific networks. This section focuses on the networks made up of organizations, which specifically provide services for families with dementia, or include families with dementia as possible recipients of the services provided. The boundaries of these networks needed to be reconsidered during the analysis phase, because as aforementioned in the methods chapter, the boundaries for each country whole network were more open to allow inclusion of all organizations offering services to the older adult populations. This was decided

in order to avoid possible exclusion of organizations that do not explicitly serve families with dementia.

Discovering these networks was the fundamental motivator of this study.

Learning that services for families with dementia exist in the Central American countries of this study, is in itself an important finding. Besides the Alzheimer's associations, which are all members of the federation of the association Alzheimer's Disease International, (Panama is in the ADI Membership Development Programme), and listed on its website, the other organizations and the ties between them were unacknowledged. Furthermore, the perspective of families living with dementia, and how they are connected to the network of service providers was also uncharted.

In this section, the structure measures, density and centrality, of the five dementia specific networks will be described and compared, and the positions of the families will be discussed.

Table 52 Dementia specific network property measures

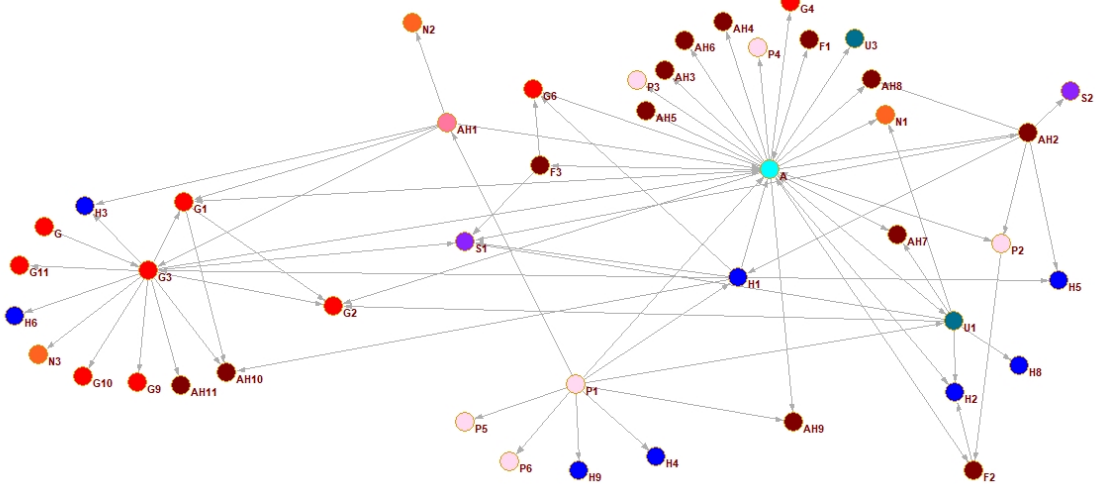
Country	Guatemala		El Salvador		Honduras		Costa Rica		Panama	
Network Measure	N =	Score	N =	Score	N =	Score	N =	Score	N =	Score
DENSITY	45	.084	27	.107	27	.15	21	.176	16	.296
CENTRALITY	45	.6	27	.404	27	.391	21	.454	16	.228
CENTRAL NODE	45 / A	.71	27 / AH	.632	27 / G-AH	.561	21 / A	.571	16 / A	.522
E-I index	45	.699	27	.907	27	.688	21	1	16	1
QAP correlation*	recip	.187			I+R+C	.297	referral	.122	R+C	.189

N=total number of nodes + most central org type; \*significant scores only

In Guatemala's dementia specific network, density was low and centrality was very high (Table 53). From the visualization (Figure 26), the network appears orderly, with groupings formed, except in the middle area where organizations are connected seemingly by chance. The central nodes are the Alzheimer's association (turquoise), a government agency (red), and a private (pink). As shown in the table, the Alzheimer's association is the most central node in the network and is connected directly to each of the groups. This is a highly

centralized position, benefiting coordination, with potential access to everything that is exchanged.

Figure 26 Guatemala: Dementia specific ties



The families are tied to the Alzheimer's association, yet not to each other. Two of the families are also tied to two other organizations, but none connected to the other main groups. In the interviews, families expressed their surprise in learning about the number of service providers existing. They were disappointed in their lack of awareness, but also desperate to understand how they were expected to discover the network on their own. All three families were passed the Alzheimer's association contact by word of mouth from family acquaintances. Therefore, no participant of the dementia specific network provided inclusivity by way of referral. In fact, the families are not present in the referral exchange ties network (Figure 27). As mentioned in the methods chapter, families were specifically asked if they were referred to or by any organization. Although the organizations in the network claimed they refer families to other organizations, the families included in this study had clearly not been of those.

Figure 27 Guatemala: Referral exchange

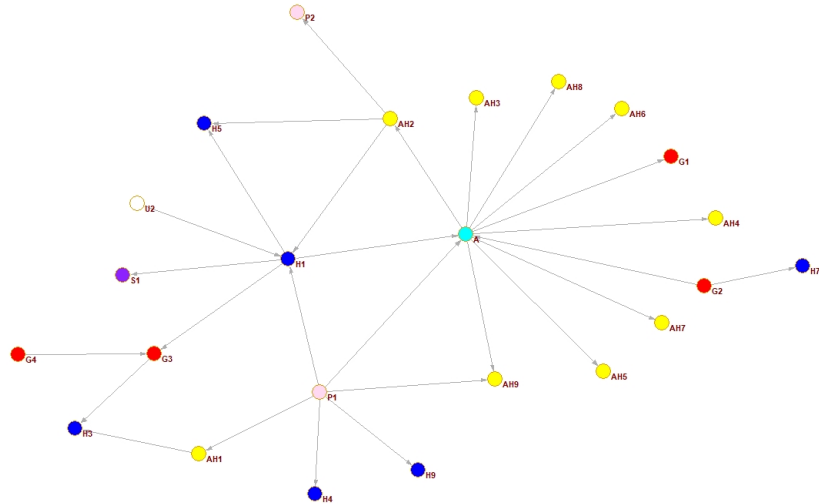
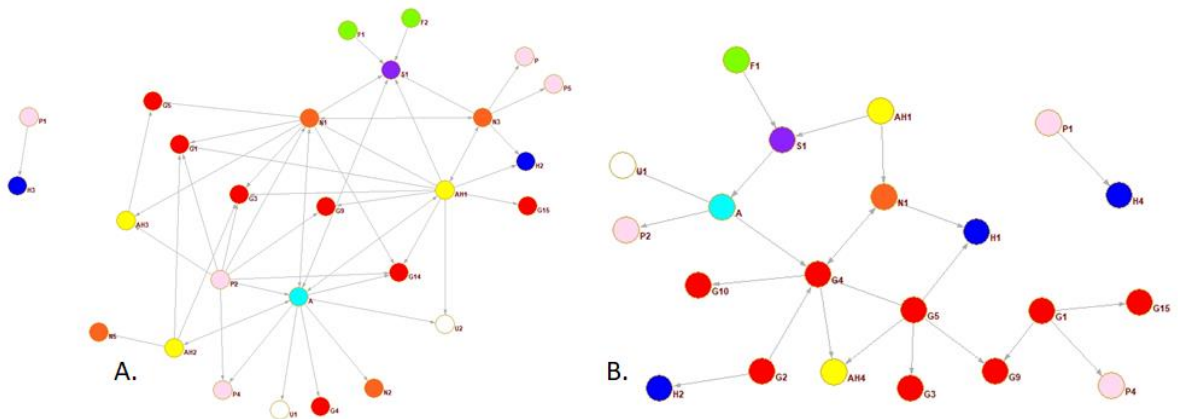


Figure 28 shows the dementia specific ties network of El Salvador. Density was high, in relation to the rest of the countries, but only 7% of all possible ties were realized. The closeness centrality of the network was also low, evidenced in the visualization. Two nodes appear most central, the Alzheimer’s association (turquoise) and a care home (yellow), while other nodes seem to be central to smaller groups. The care home (yellow) is the most central node of the network, having the shortest path to all the other organizations.

Figure 28 El Salvador: A. Dementia specific ties, B. Referral exchange

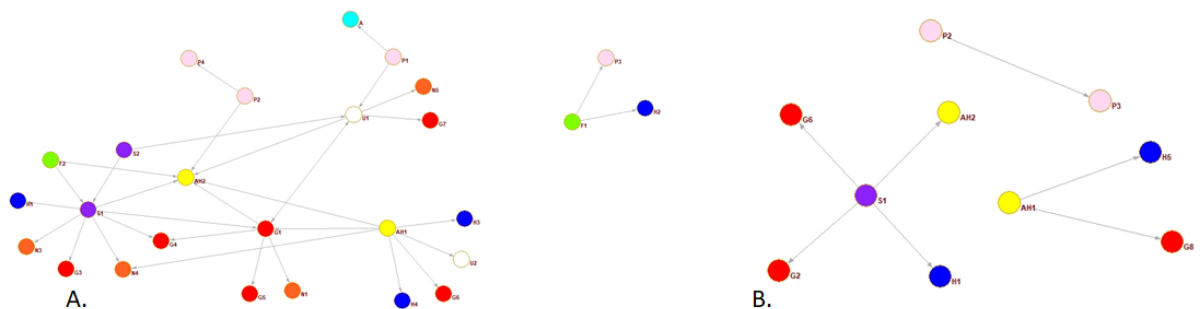


The families (green) are quite obviously on the outskirts of the network. They are connected to the same social security service provider (purple), yet are not interconnected. The interviews confirmed their lack of awareness of any other

services for families. Why did the social security organization not connect them to the other organizations they were tied to? This peculiarity is reinforced in the referrals exchange network (Figure 28) and lead back to the context chapter. In an environment where funding is scarce, the number of clients an organization has certainly helps make a claim for priority. Additionally, the aim for acknowledgement by individuals emerged as commonplace. Thus, keeping closed circles furthers individual aims rather than those of the collective. The referrals network is similar to the dementia specific network, having 2 separate components. This network does evidence that the family (green) could have been referred to the Alzheimer's association (turquoise). Unfortunately, ties between the families and the Alzheimer's association were not claimed in the interviews.

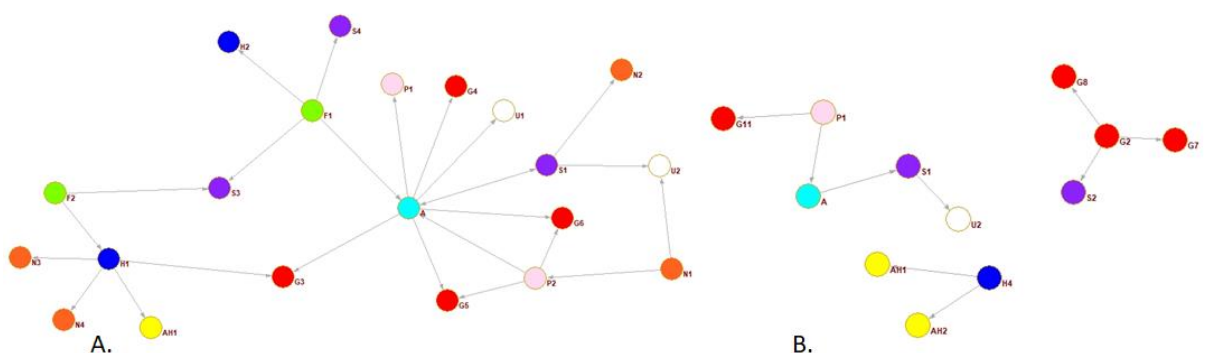
In Honduras (Figure 29) the dementia specific ties network was low in both density and centrality scores. Five different groups emerge with one a disconnected, separate component. A government node and a care home node are the most central in the network, acting as connectors of the groups. One family is totally disconnected from the main network, while the other has 2 ties, and much closer to other nodes. The Alzheimer's association (turquoise) is distant from the main network, most likely because of its status of inoperation. The context plays an important role in this network as well, in a politically polarized country, efforts of collaboration were stifled. Figure 29 portrays there referral network situation meaningfully. Three separate components with less than half of the organizations in the whole network make referrals.

Figure 29 Honduras: A. Dementia specific ties, B. Referral exchange



In Costa Rica, the dementia specific ties network has low density and middle range centrality. Figure 30 depicts the Alzheimer's association (turquoise) as the most central node, which was constant in all of Costa Rica's networks. One main group is interconnected to two smaller groups, which are also connected. With the exception of the few nodes on the outside of the main network, this structure could permit a coordination of the network and exchange. One of the families (green) is the centre of its own small group, while the other is more on the outskirts, and they have one node in between them, which has not connected them. In the referrals network, the three separate components underline the reluctance to refer. Competitive individual egos were prominent in this context, as described in chapter 5 and confirmed through these findings.

Figure 30 Costa Rica: A. Dementia specific ties, B. Referral exchange

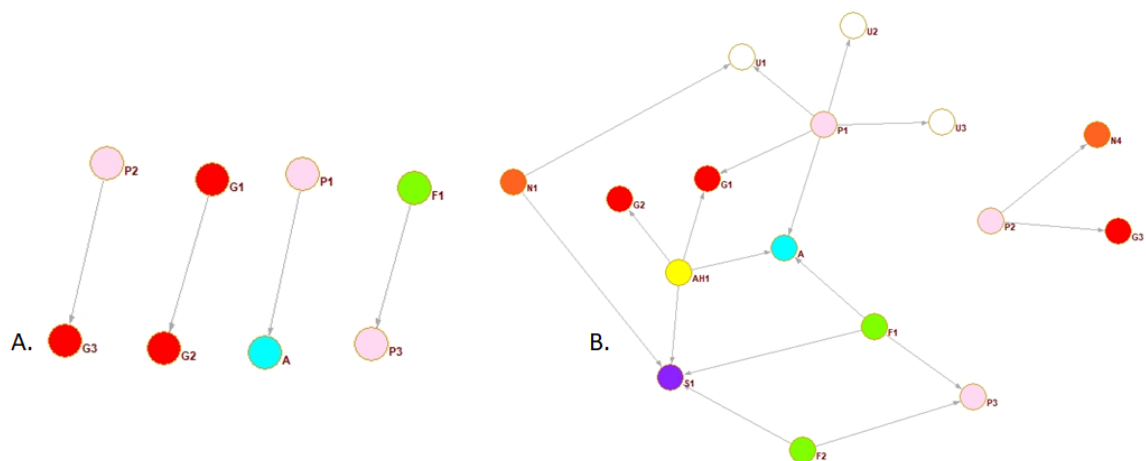


In Panama, the density of the dementia specific ties network was relatively high when using the other countries' scores as a frame of reference. Centrality of the network was the lowest of the five countries. The most central node was the Alzheimer's association (turquoise), which appears to be in the centre in Figure 31, but the network is visually fragmented. Consisting of two separate components, the structure of the larger of the two does not facilitate exchange nor potential coordination. The organizations are spread out, tied to an average of two other organizations. The families (green) are, as in the other countries, linked to

two of the same organizations but not interconnected. The referral network (Figure 31) offers an explanation to the families' positions. The referral ties are less of a network and much more pairs of organizations linked. The family in this network, claimed to have been referred to the private organization (pink), which justified their type of tie. Nevertheless, referrals were made by chance rather than habitually, again confirming the context of lack of awareness within the network.

The dementia specific networks, taken independently, reflect the general results. Low density indicates between 4% and 7% of all possible ties existing. Levels of coordination, by means of having many connections, being tied directly to many organizations thus allowing for rapid information sharing within the network, result moderately high in Guatemala, El Salvador and Costa Rica, yet remain low in Honduras and Panama. A majority of external ties was found in the dementia specific networks, laying the groundwork for multi-disciplinary and multi-sectoral connections. Yet dementia specific ties were found associated only with referrals, and the multiplex ties IRC (information, resources, collaboration), and RC (resources, collaboration).

Figure 31 Panama: A. Dementia specific ties, B. Referral exchange



These findings portray a solid base to build integration on, within the dementia specific networks of Guatemala, El Salvador and Costa Rica, who have the centrality for coordination, and ties to a variety of types of organizations.



In general, integration levels are low in the dementia specific networks. Although a few countries may have a head start to building capacity for integration.

## Family networks

The roles and positions of families within the networks have been illustrated secondarily in this chapter; priority was given to the types of networks and network measures. In this section, the focus is the families. In order to increase the quality of life for families with dementia, access to a range of support including information and formal care is imperative (Broda et al. 2017). This section illustrates the access families have to services by way of their positions and their ties. Every network that includes a family is displayed by country. The aim is to offer a consolidated view of families' places in the various types of networks, in which they are present, occurring inside a service system.

In Figures 32-36, the green circles representing families are visible in each sociogram, not to be confused with the turquoise circles representing the Alzheimer's associations. To pertain to a network, a family claimed having a collaborative tie with an organization, or claimed to exchange with that organization what is exchanged in that network (information, resources, collaboration, referrals, or a multiplex tie combining those). The purpose of visually displaying the networks, in which the families partake, is to make evident the consistent position families have throughout the networks and the countries: the outside. The fewer the ties, the more external an organization will be. Families can consistently be found in the outermost parts of the networks as explained by two of the families:

*“Care homes don't accept mom because of [her] dementia.”*

*“Everything [services] is private [for dementia].”*

This recurs in every country and underlines families' lack of access to the variety of services provided in the networks.

Figure 32 Guatemala: networks with families

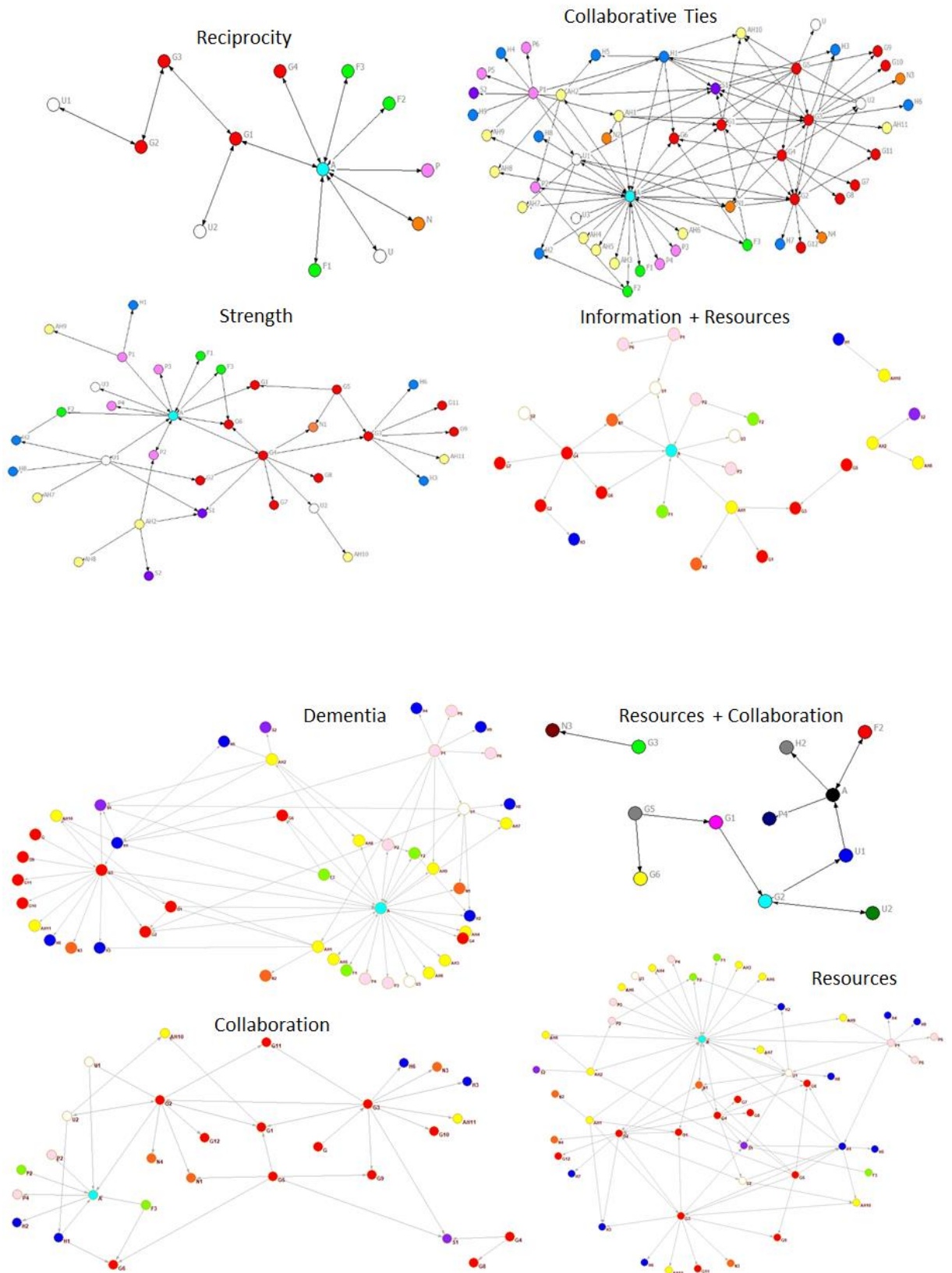


Figure 33 El Salvador: Networks with families

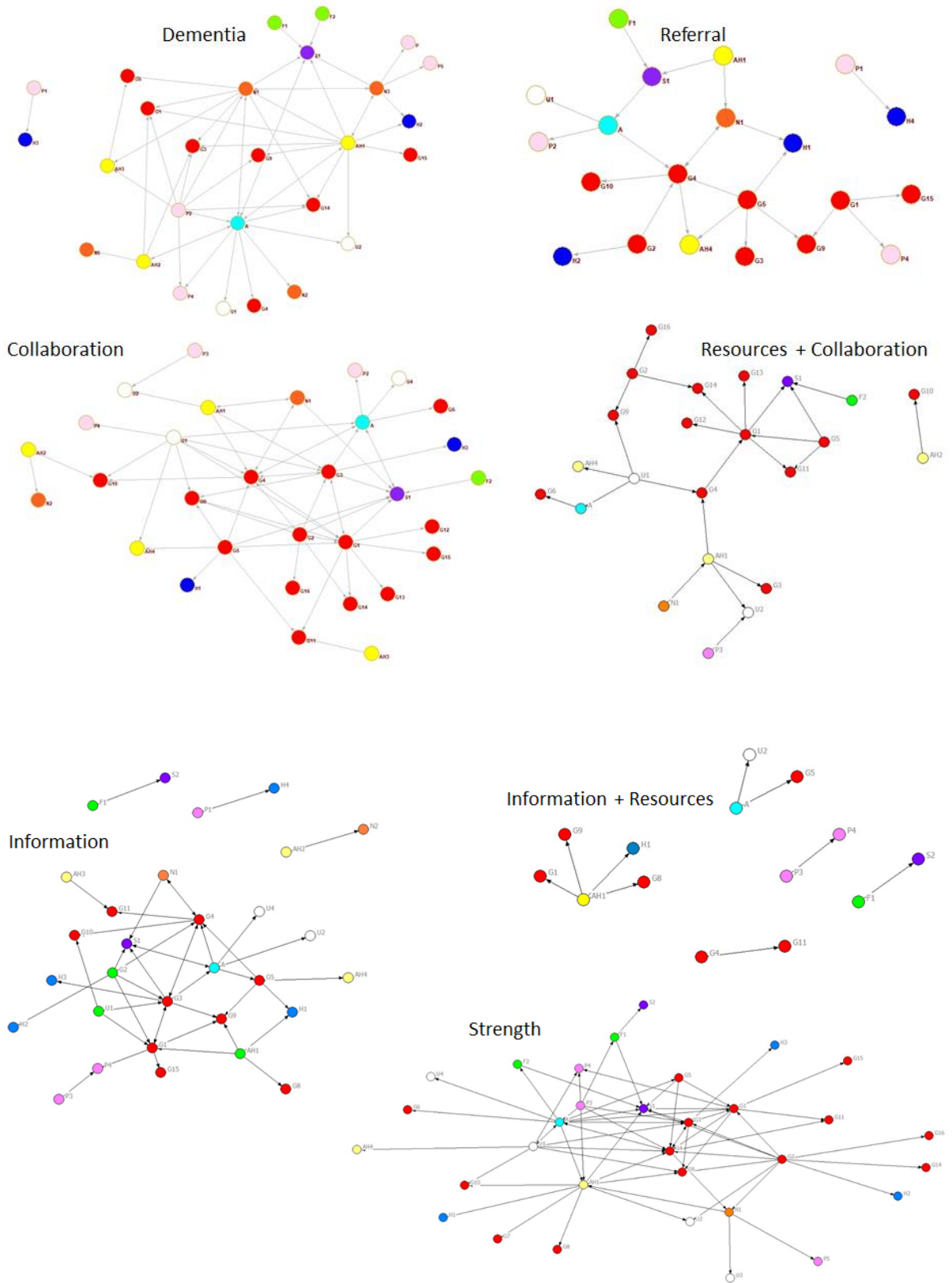


Figure 34 Honduras: Networks with families

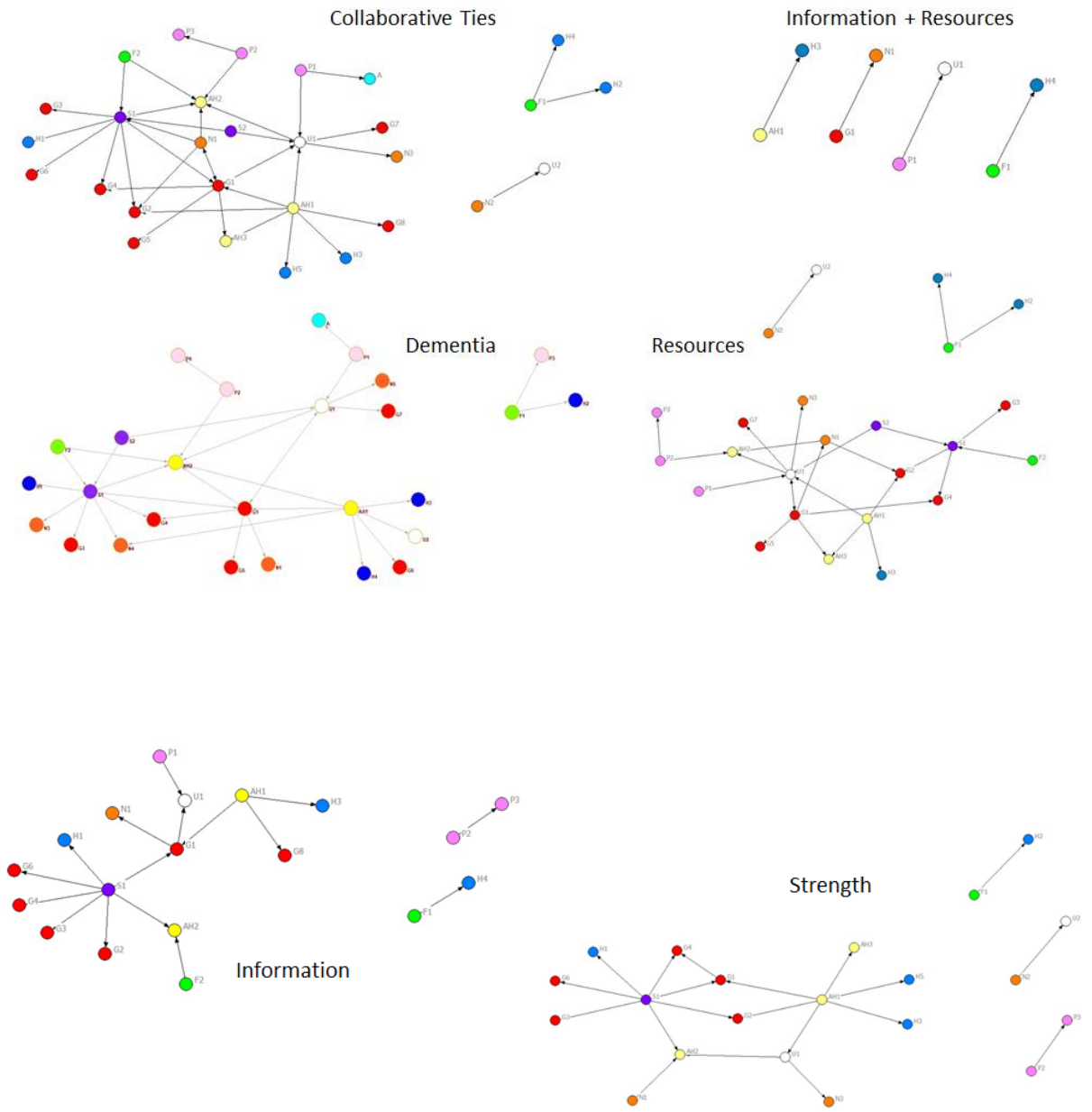


Figure 35 Costa Rica: Networks with families

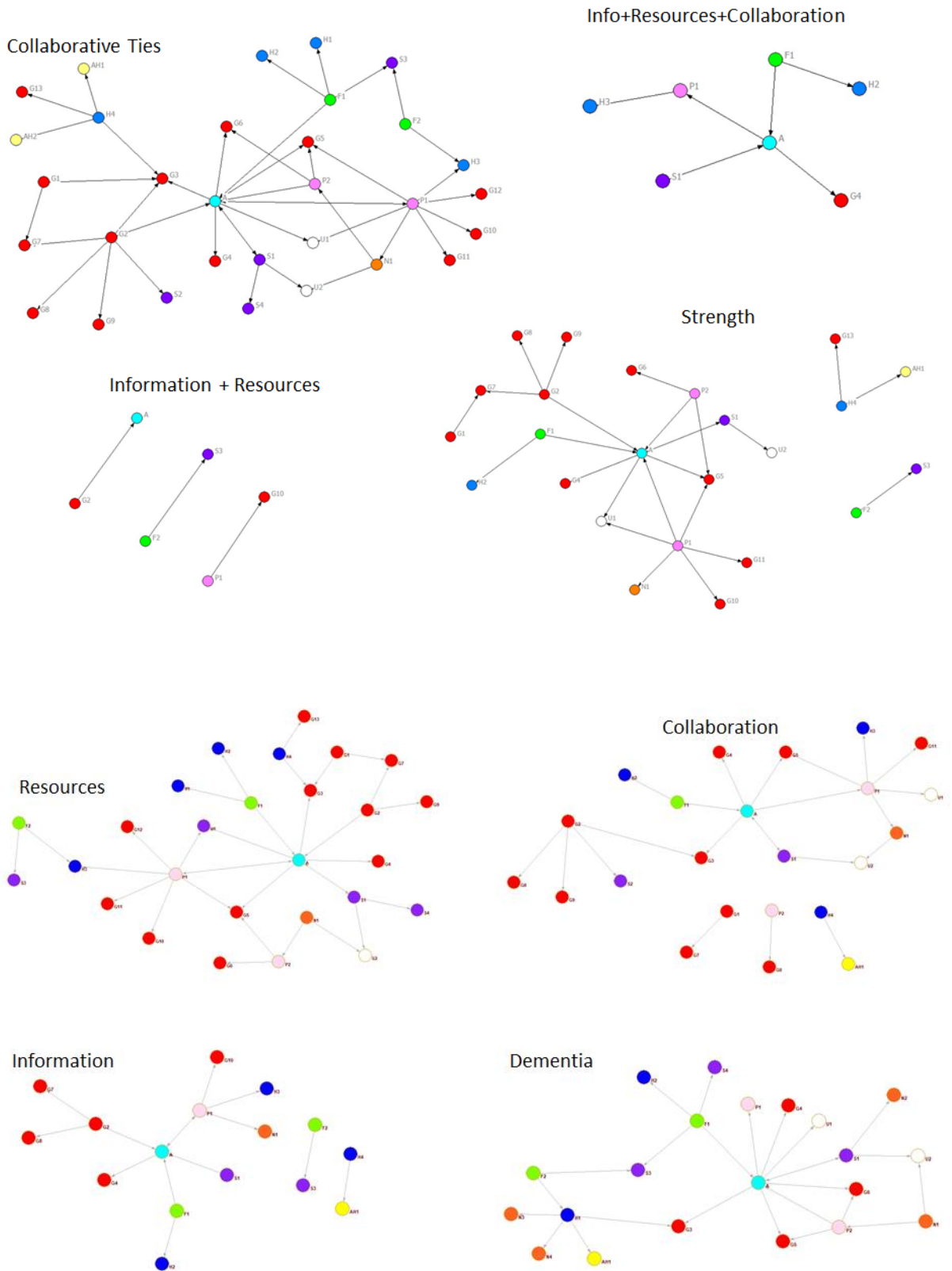
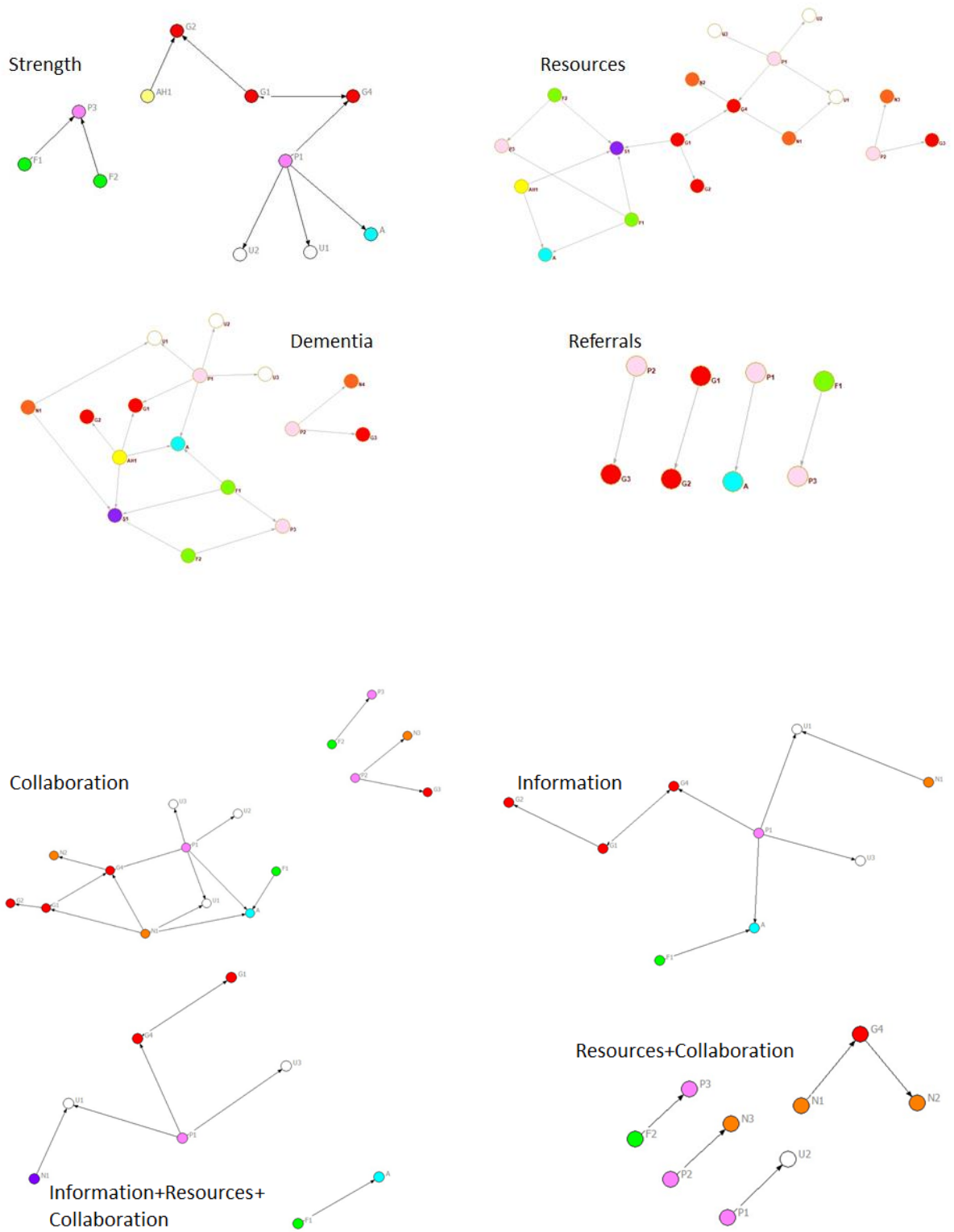


Figure 36 Panama: Networks with families



Furthermore, surprisingly, families are never connected to each other. During the interviews, I asked families whether they participated in support groups or learned new information or received advice from other families with dementia. The general response was no. Although some families who attended workshops in a memory clinic did encounter other families, time restraints coupled with a reserved culture of not sharing personal grievances resulted in families not linking with each other. This pattern in all five countries, of families being so close, linked to the same organizations, yet not linked to each other, compels more reflection on the contexts. The benefits of peer support for families with dementia, outlined on the website of the UK Alzheimer's association, include learning how to cope and manage caring for a loved one. A systematic review by Dam et al. (2016), of social support interventions for caregivers such as support groups and befriending programs, found that caregiver well-being improves.

These findings portray a clear picture of the isolation families with dementia endure. In addition, the failure of the networks to cooperate by referring families to and amongst each other is a recognized phenomenon internationally, where "contact with [a] first care provider rarely result[s] in an immediate and effective referral" (Volpe et al., 2020, p.168). The failure to offer multidisciplinary and multisectoral support strengthens the underlying idea of this thesis. Integration could facilitate the navigation of the care and support networks.

## Conclusion

In general, the findings portray networks with low density, where organizations are actualizing approximately 10% of the connections they could make. The relative centrality of organizations within the networks is low to average, signifying that moderate coordination of the connections, and exchange between them, exists. As the positions of the families in the networks demonstrated, it is not enough to coordinate referrals to offer families interdisciplinary support or integrated care. As Broda et al. (2017) found, families need someone to assist them in coordinating their care and guiding them across potential services.

The high fragmentation is highlighted in the dementia specific networks. Across organizations that share a highly specific population to whom they claim to provide services, a shortage of communication ensues. Incorporated in the shortage are the families, lacking interconnection. A referral system needs to be in place (Ferri and Jacob, 2017) which includes linking families to each other for support. The intricacies of the interconnections of the families is a topic outside of the scope of this thesis. Relevant to this study is the resulting lack of support perceived by the families, and the correlation proposed by this thesis between that missing support and the fragmentation of the networks, echoing the proposition that care delivery fragmentation is an undertaking at the system level (Provan & Milward 1995, Nicaise et al. 2013).

In the next and final chapter, the findings are discussed in relation to the research questions. The final assessment of the older adult and dementia service systems resulting as partaking in a low level of integration is also reviewed. The impact and implications of this study are presented and the limitations, along with recommendations for future research, are considered. The main ideas of this study are highlighted throughout the chapter, that an older adult and dementia service system needs to be integrated in order to provide multidisciplinary care, and that interactions are indicators of integration.



# Chapter 8: Discussion

## Introduction

This study explored how older adult service systems in five Central American countries are structured, and how the interorganisational relations in those systems link to integration. The overarching objective of this study was to evaluate the integration levels of each of the five systems.

This study was framed through a critical realist lens, which posits that the discovery of underlying social substructures and mechanisms of social events is an essential root of social scientific knowledge production. The exploration of seven indicators, allowed for interpretations of interactions to be assembled into a reality of the networks in existence.

The results indicate that system density and centrality measures were low, indicating general fragmentation and low integration. Yet the systems also included multiple and high indicators of linkage development, such as the exchange of resources and information, external ties, and an overall sense of collaboration. Findings portray a quid pro quo culture of exchange between organizations with underlying strong, collaborative ties. Families are excluded in the exchanges and are consistently unaware of services especially those specifically for dementia. They remain on the outskirts of the networks, barely connected, and mainly unaware of the services available. Families are not referred to other service providers in the networks because most participants of the networks are ironically just as unaware of the networks. Low-density levels are evidence of this obliviousness, where approximately generally only 10% of all possible ties are actualized.

The findings bring to light active older adult services present in five small countries of a region practically neglected in the global ageing literature. The key elements of the biopsychosocial model of care and of integrated care, multidisciplinary and multisectorality, necessary to meet the complex needs of families with dementia

(Gould 2011, Nicaise et al. 2013, Fox et al. 2013, Bunn et al. 2017, Provan and Milward 1995), were found to prevail amongst the ties between service providers. Based on the findings, these service providers survive in territories where the limited available funds are allocated to other pressing issues such as poverty and violence, by the ancient social norm of exchange. Social exchange theory states that interactions are based on exchange, (Emerson 1976, Foa and Foa 2012, Blau 1964), and organizational theory frames inter-organizational ties as based on advantages and disadvantages, or analyses of costs and benefits (Provan and Milward 1995). This will be discussed further in the subsequent exchange section.

This study mapped the ties between organizations within each service system, and acquired an understanding of the meanings of those interactions by way of participants' perspectives. Providers of services for older adults and families with dementia were the target population. Over a 10-month period, I visited 5 countries for approximately 2 months each, completing 68 semi-structured interviews of representatives of government, public, private, non-profit organizations, hospitals, care homes, and universities, as well as families.

First, I will outline the findings, grouped by their relevance to the research questions, and link them to some of the theory and literature discussed in the beginning chapters. Subsequently, I will explain the impact and implications of this study, and offer some of its limitations. How my findings contribute to practice and policy will lead to the final section on future research ideas to accompany and further enhance the findings of this study.

## Research Findings

In this section, I reiterate my research questions linking the main findings to the theories and research previously discussed.

### Structure of Older Adult Services

The first main research question and sub questions were a means to develop a broad view of each country system, allowing for a basic charting of available services previously unbeknownst. Knowledge of service systems is lacking and is

necessary to create care pathways, detecting overlap, and informing policy makers (Hallberg et al. 2013). This mapping allows for a critical review of services offering families, providers and governments' insight into the range of care services available and identifying gaps (Fitzgerald and McLoughlin 2016, Blanchet and James 2013).

1. How are older adult services structured in Central American countries? What are the relevant regional and national policies, what services are offered; what types of services are dementia specific?

The value offered by global policies is to set standards and guidelines for the development of national policies, which mandate advocacy, and protection of older adults' human rights. "(..) strategies should be developed and applied to address national variations in health care systems but also to ensure equality of access to treatment and essential standards of dementia care worldwide" (Volpe et al. 2020, p170). More precisely, national older adult and dementia policies allow for respect of the division of labour in a care system that is fundamental to integration (Nies 2004), where participants of a network acknowledge their role and responsibilities and those of other participants.

Each country in this study has a law advocating for the rights of older adults; Costa Rica has a national dementia plan, and El Salvador's plan was awaiting ratification. In parallel, every country has a commission on ageing. For integration to grow, legislative systems must facilitate compatible governance among diverse sector organizations (Nies 2004, Shaw 2011). Although the primary foundations have been laid, absent coordination amongst providers is evidenced in the subsequent findings, and attests to a need for policy acknowledgment and adherence, and perhaps more specific national regulations. An example from the findings worth recapitulating is Guatemala's national entity for regulation of older adult care facilities. The only one of its kind found in this study, it is a concrete action by Guatemala in their movement to protect older adults.

I travelled to an under researched region and found undocumented service systems made of a variety of organizations aiming to practice person centred care.

Nine types of organizations providing services to older adults emerged from the thematic categorisation, as described in chapter 5, of the total 167 organizations. Slightly more than half claimed they either inclusively or exclusively offered assistance to families with dementia. The dementia care and the integrated care literature substantiate the need for multisectorality and multidisciplinary in service provision to meet the complex needs of people with dementia and their families (Engel 1977, 1981, Nicaise et al. 2013). The findings show providers from various sectors and disciplines operating in each country. Diverse services were offered ranging from care homes and day centres to memory clinics.

The findings can be understood in accordance with Strandberg-Larsen's definition of integration (2011, p.7),

“Focus is on providing the population and/or high risk groups within the population with services needed for optimization of population health. This perspective will often go beyond the realm of healthcare, and coordination of services will therefore also be expanded to include social care services or similar.”

Thus, the differentiation of types of services and organizations is an element of integration, and the countries in this study were similarly varied in the services provided. The assessment of integration based on the findings of policies and types of service providers proves the basic groundwork for creating integrated care systems is in place.

## Connections and Networks

The second research question and sub questions prompted the dissection of indicators of integration, thereby leading to a punctilious analysis of the node and tie attributes, and of network measures. The selection of indicators of integration was fundamental in structuring through which aspects of the networks the levels of integration would be assessed.

2. How integrated are the networks? What integration levels do the node & tie attributes suggest; what integration levels do the network measures suggest?

I created a theoretically informed framework for assessing the levels of integration within the health and social care service networks of developing countries. As explained in the methodology chapter, the methods and indicators used in this study were assembled through thematic data coding and guided by literature of previous studies on health system integration. Three subjective indicators: type of tie, strength of tie, type of exchange; and four network property measures were used (Morrissey et al. 1985, 1994, Milward and Provan 1998, Rosenheck et al. 2001, Blanchet and James 2012, Davis et al. 2012, Nicaise et al. 2013, Raeymackers 2013, Wang et al. 2016) and are discussed in turn here.

#### Types of ties and strength

The foundation of both the biopsychosocial model of care, and system integration, is collaboration of and between disciplines, sectors, and organizations. Findings depict existing ties as collaborative and very strong, but most were not associated with any explicit alliances or agreements, and where these agreements existed, they were verbal and/or informal. Contrasting Pieper's (2004) claim that organized arrangements sustain integrated care, correlating to the element of coordination, the Central American systems resulted as not having organized relationships. These results represent a conducive social environment at a linkage level of integration, with a need for structure. A network where participants perceive ties as collaborative and very strong demonstrates willingness and ability to collaborate. Non-profits in El Salvador, Honduras and Panama claimed most of their very strong and collaborative ties to be with government agencies. If Hasnain-Wynia et al.'s (2003) hypothesis is true, that actual effectiveness and perceived effectiveness of a partnership both depend on who participates, strong and collaborative ties with the leading provider of public health and social care, government, will positively affect collaboration.

#### Exchange

Exchange is confirmed as an indicator for integration in the health system integration literature (Morrissey et al. 1985, 1994, Milward and Provan 1998,

Rosenheck et al. 2001, Blanchet and James 2012, Davis et al. 2012, Nicaise et al. 2013, Raeymackers 2013, Wang et al. 2016). The data confirms resource exchange as the most persistent of the four main exchanges: information, referrals, resources and collaboration. The prevalence of the exchange of resources contrasts Fried et al.'s (1998) findings of resource sharing as a "rare phenomenon" (p.39) in rural areas of the United States, potentially rendering these findings unique to a developing country context.

The most common form of exchange was multiplex, ties partaking in two or more exchanges, resources and collaboration in El Salvador, Honduras and Costa Rica, while resources and information was the most frequent multiplex tie in Guatemala, and resources, collaboration and information in Panama. Resources was the ubiquitous exchange category, and included tangibles such as escorting, infrastructure, knowledge, research, training, and funds by means of donations, discounts and sponsorships.

To achieve their main goal, survival, organizations need resources that they may not have, but can access through exchange (van Raak and Paulus 2001). According to resource dependence theory, ties between organizations occur only when one is dependent on the other for some resource, creating inter-dependency (ibid). Through this process of establishing ties, a system develops (ibid).

The Central American networks in this study comprised chiefly of inter-dependent ties, confirming the development of a system. For example in El Salvador, 86% of 91 ties exchanged resources, indicating that a system has developed, unbeknownst to the participants. Interviewees described a context of competition with and criticism of each other, and an intense sense of individualism prevailed. How the system participants perceive the network of service providers completely contrasts the actualized inter-dependence, indicating a desperate lack of coalition culture and leadership, and underlining that El Salvador's inter-dependent system is needs based.

Interorganisational exchange is also considered a means to developing "multi-scale solutions to multi-scale problems" (Blanchet and James 2012, p443) and can lead to achieving shared goals in a shared effort. These are the basis of the

biopsychosocial model of care, whereby an individual's comorbidities and complex needs are assessed, managed and coordinated across all of the dimensions: biopsychosocial-environmental-spiritual. The informal inter-dependence, in El Salvador's and the other service networks, could be strengthened through formal alliances, created in a process of integrated system development, outlined subsequently. Formally pooling resources is an element of the full integration level of Leutz's model (1999) as adapted by Shaw et al. (2011), and further establishes the reliability of contracts and/or agreements. The frequent exchange of resources within the networks albeit informal, adds further robustness to the linkage level of integration assessment.

#### Network properties

Low density was revealed in all networks in all countries, not surprisingly. Based on Valente et al.'s Goldilocks principle (2015, p.7), just the right amount of density must be established where moderate levels appropriate to knowledge sharing and harmony between actors. Low and high density both hinder cooperation by creating barriers to the flow of information and resources due to lack of capacity, too few ties, or too many causing chaos. Network density scores for the five countries were all low and extremely close, indicating circa <10% of all potential ties were actualized. Density is an indicator of integration as a measure of cohesiveness or the development of linkage among service providers enabling exchange (Provan and Milward 1995, Nicaise et al 2013). These systems may boast a variety of types of organisations and services, but if interconnectedness is absent, the capacity of the networks to supply continuity of care is limited (Provan and Milward 1995, Leutz 1999). Observed unawareness of organizations within the system during the interviews was confirmed by the density scores as well as the needs based structure relating back to the absence of formal agreements (Kwait et al. 2001).

Consistent with the findings on families' positions in the networks, the lower the density among organizations, the less likely families will have access to services to meet their multiple needs, impeding the implementation of a biopsychosocial model of care (Morrissey et al. 1994, Engel 1977). By knowing which

organisations have relations with which, and what they exchange, new ties based on needs can be built (Milward and Provan 1998).

Coordination is directly linked with the network property centrality (Freeman, 1978, Nicaise et al. 2013, Morrissey et al. 1985), and is one of the basic elements of integration and integrated care (Leutz 1979). Decentralized connections lead to complex coordination of services. Centrality scores showed Guatemala, El Salvador, and Costa Rica's networks as generally moderately centralized. These findings may be associated with the low density scores, where few organizations are linked, which would be consistent with the assumption that an organization can manage only a certain number of ties effectively (Provan and Milward 1995). Furthermore, this seesaw of density and centrality is recognized in the literature, both cannot be maximized contemporaneously (Morrissey et al. 1994). Simultaneously, El Salvador, Honduras, and Costa Rica's exchange networks were highly fragmented, and made of multiple components. These results highlight a lack of coordination concentrated in networks of ties exchanging resources and multiplex ties. Based on Freeman's (1979) concept of centrality and De Nooy and Bataglj's (2005) description, the organizations within the exchange networks have few ties, meaning they interact and are interacted with few others, and can influence and be influenced by only a few in the network. This points to absent leadership, and predominance of independent ties as opposed to linked networks. Exchange could increase through a coordinated effort, allowing organizations more selection and available resources, directly impacting care provision through an increase in referrals and information sharing.

The Alzheimer's associations emerged as the most central nodes in Guatemala and Costa Rica, in accordance with my perceptions of these organizations' leadership and in Costa Rica's case, control of who interacts with whom. The centrality of the Alzheimer's associations, not indifferently providers of services exclusive to families with dementia, would be beneficial for client outcomes, according to literature on centrality (Fried et al. 1998). The Alzheimer's association has a major connective role in these networks. This role could be exploited further: to enhance person centred care through case management by a dementia specialized organization; by acting as the point of reference for other



organizations; and through correct interpretation of complex, dementia specific behaviours (Kwait 2001, Fried et al. 1998).

Government nodes proved central in El Salvador, possibly because the system comprised of 43% government nodes. Government agencies seem to be the glue holding El Salvador's networks together. Yet considering the context, this potentially depicts a situation where government practice authoritarian control, which could pose a challenge for social services development (Cruz 2015).

Of particular interest is the finding that high fragmentation occurring only in the exchange networks portrays a dissonance within the systems of El Salvador and Costa Rica. Both have one prominent central player across their networks, yet in the exchange networks, the central node does not appear to have any clout. In these networks, organizations have ties independent of the larger groups. This reaffirms the need for formal agreements, and collective goals.

In comparison, Honduras and Panama are more symmetrical, where no one organization or group of organizations have dominant roles, indicating that the existing ties are generally not dependent on any one or group of organizations. Coordination according to Strandberg-Larsen (2011) is a method of cooperation with collective goals and explicit roles and responsibilities, which leads to integration. In Leutz's levels, coordination is the level that provides operational structure and regulations relevant to exchange among network members. Moderate centrality scores in the four countries mentioned above provide consistency to the assessment of strongly linked system foundations on which to build on. Additionally, Guatemala, Costa Rica and El Salvador feature clearly defined, yet informal, coordinating organizations, yielding the development of integrated systems.

As aforementioned, multidisciplinary and multisectorality are essential elements of integration, and of continuity of care, and more specifically to providing the biopsychosocial model of care. The purpose of E-I index analyses was to investigate these fundamental sectoral interactions (Gallelli 2016). I argue that the 'perfect' external to internal ratio in care service provision networks, not found in the literature, would need to apply a 'Goldilocks' measure, where too few external ties are a barrier to multidisciplinary and multisectorality but too many external ties

are also a barrier to knowledge and referral exchange of providers of like services. The ratio of external to internal ties shows realized diversification. Generally, E-I index scores indicated organizations partook in more external ties than internal ties across the networks and the countries, thus upholding the aforementioned important elements of integration.

While the E-I index analyses indicated individual organizations' interactions, QAP analyses assessed whether one type of network is correlated with another type of network, or a tie of one type existing between two actors, increases (or decreases) the likelihood that a tie of another type exists between them (Sonnenberg-Klein 2017). Correlation scores between referral networks and 6 other networks were found to be highly significant across the 5 countries, indicating the exchange of a referral fostered other exchanges. Two multiplex types of ties also resulted as correlated to other networks in 3 countries.

These are interesting findings that suggest ties exchanging referrals, RC, resources and collaboration and IRC, information, resources and collaboration are reinforcing ties (Hanneman and Riddle 2019). The reinforcing ties emerge in separate settings, thus indicating a potential contextual influence. The exchange of referrals in Panama presents a means to interconnection, an important linking element between health and social care organizations that can directly impact care outcomes (Provan and Sebastian 1998). While the exchanges of resources and collaboration appear to be influential in the three poorest countries (World Bank 2020), revealing potential alternative means to ongoing service provision (Ferri and Jacob 2017). This is a noteworthy finding, proving economic resources are not the only manner in which health and social care services can be maintained. For developing countries, this is enlightening, and may be an answer to Ferri and Jacob's (2017) call for tailored solutions in LMIC for the care of older people. For Guatemala, El Salvador and Honduras, embracing this quid pro quo culture could lead to structuring their systems based on it, learning to depend on it and each other, in line with the aforementioned resource dependence theory.

## Dementia Networks and Families

The third research question and sub questions were dedicated to dementia care and the families living with dementia.

3. How do the dementia specific networks compare to the whole networks?  
How do the positions of families in the networks offer insight into their receipt of care/support services?

Dementia specific networks of the 5 countries comprised only of the organizations claiming to offer services for families with dementia. The organizations specific to dementia had few ties to each other, but diversified, and coordinated in every country except Panama. Findings indicated general low density, consistent with the general density measures. Networks showed moderate to high centrality scores, the most centralized was in Guatemala and the least centralized was in Panama. Coordination efforts appeared to be led by the Alzheimer's association in Guatemala and Costa Rica, and by care homes in El Salvador and shared by care homes and government in Honduras. All demonstrated mostly external ties, more than other networks. QAP correlation analyses showed the dementia networks to be associated with 3 other networks, with referrals and IRC in Honduras, and in Costa Rica with referrals. In terms of integration, although the dementia specific networks tended to be more centralized than other networks, density was too low, according to the Goldilocks principle, to allow for a seamless flow of exchange (Valente et al. 2015). Linkage level elements were present, reiterating the systems as fertile for growth.

Finally, the findings of the families' positions within the service systems explained and corroborated their claims of inadequate support. To provide care, a health system must integrate the needs of people with dementia into the social network of health care (Portacolone et al. 2014). The families were connected with 1 to maximum 3 organizations within the systems, but most importantly were on the outskirts of the networks, not being informed of or referred to other available services. Sparse connections between service providers is correlated with

providers themselves being unaware of each other, and families unaware of what the systems offer, and therefore not receiving support. It is well documented that families with dementia have poor access to information and services, in part attributed to individual circumstances and in part to systemic limitations (Gajardo et al. 2017, Broda et al. 2017, Bieber 2019). This study evidences the systemic limitations pertaining to the ties and interactions between service networks and families.

## Summary of Findings Discussion

Describing strengths and weaknesses of a system help implement innovations (Blanchet and James 2012, p.443). The strengths of the five Central American older adult services systems of this study were the variety of disciplines and sectors, exchange, diversified ties, coordination, and solidarity. The weaknesses of the systems were the absence of dementia specific regulations and formal alliances, low density, and the segregation of families with dementia. The elements described above led to the conclusion that the five systems presented a linkage level of integration, which includes the capacity to grow more integrated. In sum, and reiterating, the foundations for integrated dementia service systems have been laid in the five countries studied. In conformity with two strategies of developing integrated systems, the findings show Guatemala, El Salvador and Costa Rica as having taken an actual, measurable, first step. The first step of van Raak and Paulus' (2001) interorganisational network development strategy, and of the PRISMA model (Program of Research to Integrate Services for the Maintenance of Autonomy) (Herbert and Veil 2004) is coordination. Following these strategies, this step encompasses a presence of structure enhancing collaboration amongst organizations, and a steering of interactions. Though the coordination efforts of these country systems were informal and largely based on resource exchange, this naturally occurring collaboration and strength of ties facilitates the development of integration.

Next steps for these countries entail roundtables to solidify the cooperation of the networks through collective decision making on key points:

following van Raak and Paulus' (2001) interorganisational network development strategy:

1. Steering interactions
2. Knowing goals of all and each
3. Knowing means needed by all
4. Conformity to rules compliance;

the six components of the PRISMA model (Program of Research to Integrate Services for the Maintenance of Autonomy) (Herbert and Veil 2004):

1. Coordination of all organizations involved in delivering health and social services
2. Single entry point
3. Case management
4. Single assessment tool
5. Individualized service plan
6. Computerized clinical chart.

Subscribing to a common purpose is the second ingredient in partnership working according to Hasnain-Wynia et al. (2003), and the second component of van Raak and Paulus' (2001) strategy above. I advocate that this be a fundamental next step for all five country systems, and that the focus be to meet families' needs, as indicated by Suter et al. (2009), as one of 10 key principles in system integration, and previously described in chapter 2.

Each country's commission on ageing should take responsibility in growing the ties between service providers and consolidating the dementia specific networks. Singularly, Guatemala's Alzheimer's association certainly led the national collective efforts to structure and coordinate dementia services. Partnered with the commission on ageing, they could co-design the formal structure of the dementia network. El Salvador's department of older adults within the Ministry of Health was in a prime position to support the leadership and coordination that the commission on ageing should be taking in formally structuring the dementia specific services network. Honduras vaunted the unique older adults centre for integrated care (CEAIAM) that already is an acting hub for older adult services, and could easily be transformed into a central coordinating centre specific to dementia services. The commission on ageing in Costa Rica and the Alzheimer's association could work in partnership to formalize a structure for the dementia services network. Finally, Panama needs to induce both their commission of

ageing and the Alzheimer's association in operation, to take the reins on building and shaping the dementia services network.

Integration may be formal or informal, it may require simple exchanges or multiplex exchanges, and it happens "when organizations that provide services to a particular client group work together to coordinate the services these clients need" (Provan and Sebastian 1998). Most importantly, "an integrated [care] system is a prerequisite for integrated care" (Wang et al. 2016).

## Impact and Implications

The potential impact of this research motivated me to maintain a continuous vision of this study as a whole, forcing me to move back and forth through the micro level of the organizations, to the meso level of the networks, and to the whole systems perspective.

The analysis of the interorganisational interactions provided a detailed and previously unreported profile of dementia care systems in five Central American countries. The investigation of inter-organizational ties in a health system thus becomes a specific method of evaluating and thus implementing integration between health and social care service providers.

The immediate impact made in fieldwork was producing conversations amongst unrelated organizations. Awareness of and conversations with other older adult service organizations fostered new ties, and potential new exchanges and a greater consolidation of the networks, elements of developing system integration and integrated care.

This study has demonstrated that social network analysis represents a valuable approach to producing a reliable account of system level of integration, and that inter-organizational communication can be a low-cost intervention to improving a care service system (Davis et al. 2012). This method is useful to policy makers and practitioners because it gives them a vision of the integration development process (Herbert and Veil 2004, Valente et al. 2015, Blanchet and James 2012).

Furthermore, it can help them understand what the key features of the service delivery systems are (Kwait et al. 2001).

Elder's (1976, p210) "premise that social processes transcend cultural, geographical and temporal boundaries", applies to this study which offers comparable data of similarities "in network patterns independent of differences in local or national contexts and policies" (Nicaise et al. 2013). The benefits of cross-national research include attainment of "exciting new insights and a deeper understanding of issues that are of central concern in different countries" (Hantrais 1995 web issue). According to Baistow (2000), and echoed in Mehta and Peterson (2019), we can learn from comparison research in four ways: we can learn about others, from others, about ourselves, and with others. Through this study, each country can learn about the older adult and dementia service system of their neighbouring countries and reflect on their own system structures, borrow practices and value constructive feedback (ibid, ibid). More precisely, the findings suggest that Honduras and Panama can borrow the plan for dementia specific day centres; and Panama can learn from the others how to station health and social care units dedicated to older adults and dementia, and how to enrol municipalities in the networks. El Salvador, Costa Rica and Panama could use the excellent examples of integrated care centres solely dedicated to older adults, from Guatemala and Honduras. Lastly, together with the others, Guatemala must reflect on the gap between the said will of the organizations to collaborate, and the actual interactions taking place. Ultimately, the outliers in each network, presented in chapter 5, furnish an excellent starting point for transnational learning.

The direct implications for practice and policymaking of my findings are fourfold. First, the key learning from this research is the value of building relationships. There was clear potential, for providers of care and support services for families with dementia in the five countries, to continue to build relationships, develop alliances with clear, shared responsibilities and goals, and to coordinate cooperation and collaboration, as per van Raak and Paulus' (2001) interorganisational network development theory (Suter et al. 2009). The commissions of ageing in each country can be considered launching pads for co-

designing shared aims and new interorganisational collaborations with all stakeholder representatives. The cooperation in Guatemala for example, between the Alzheimer's association, the university, and the DRACES (Department of Regulations, Accreditation and Control of Social Assistance Services), could be copied by other providers, and this practice of collaboration could be copied in other countries. This triad, facilitated dialogue between a dementia service provider, a research and internship provider, and the national regulator of social services, which informed practices for all.

Furthermore, a prime example of sharing goals is Honduras' CEAIAM (Centre for Specialized Integrative Attention to Older Adults), where the biopsychosocial model of care is the objective of multidisciplinary teams. These alliances can also incorporate families as participants of the development strategies and ultimately as recipients of the services. In addition, national and regional policymakers can define legal frameworks that advocate and sustain interorganisational partnership working aimed at older adult and dementia systems (WHO 2016, ADI 2018, 2019). More importantly, to further promote cooperation and prevent withdrawal from alliances, policy makers and network participants will need to believe that integration will lead to goal achievement, and will benefit communities (Hasnain-Wynia et al. 2003). National dementia plans may be the opportunity to set integration development standards specific for dementia service networks. A major step toward regional integration could also be for the national networks to be linked to the SISCA, the Secretariat for Central American Social Integration, as proposed in chapter 5, thereby with each other.

As stated above, one of the first steps is to set collective objectives, which should include direct outcomes such as care for people living with dementia and their families. Some initial aims can be taken from the WHO guide (2018) and from the ADI Plan to Impact reports (2018, 2019). These include supportive services for families, training for formal and informal caregivers, protocols for care, and integrated networks (Sun et al. 2020).

Second, families must be made aware of the services available to them through the actions above, in order to expect and request care and support, and collaborate with service providers. The evidence from the interviews and the networks proves families lack knowledge of the existence of a network and are not



referred in order to gain access to available services. An example of the merit of referrals can be taken from Panama. Soon after the emerging Alzheimer's association became aware of a particular private service provider, the association referred a family who was provided with a needed service they previously did not know existed.

Data from Bieber et al.'s (2019) scoping review, portrays barriers to utilisation of services by families with dementia were: their lack of knowledge of existing services, general practitioners' ignorance of available services, and fragmented and confusing systems. Proactive engagement by health and social care professionals emerged as a facilitator to accessing services (ibid), emphasizing the aforementioned actions providers must take collectively. In a study on access to general healthcare services in Colombia (Vargas et al. 2010), findings indicated barriers such as waiting times, distance of service providers, and restricting criteria requiring in person appointments. Like Colombia, these barriers were present in Guatemala, El Salvador, and Honduras, highlighting how a portion of people in need of services in these countries may potentially fall through the cracks. These consistent findings stress another vital step for network participants to collectively take, fourth in the aforementioned network development strategy (van Raak and Paulus 2001), creating structure through guidelines, such as national plans or policies, to confront the barriers to accessing care. One example of such guidelines is Costa Rica's national dementia plan, where improvement of access to integrated care and strengthening the coordination among providers are two of the ten national objectives. This step of creating national guidelines advocating access to care, sends a message to providers, and networks of providers, to pay special attention to this aspect of the dementia services systems.

Third, Central American practitioners can use these findings to increase their engagement with families with dementia, and build the capacity of their networks. By way of events such as the national Alzheimer's conferences held once per year by the active associations in Guatemala, El Salvador, and Costa Rica; and the regional Iberoamerican Alzheimer conference held every year in a different Iberoamerican country ([alzheimeriberoamerica.org](http://alzheimeriberoamerica.org)), network awareness can be increased. Practitioners, researchers, and families with dementia attend these conferences as well as other local events. Service providers can pool resources,

for example print handouts and create websites for the older adult and dementia service networks, to inform the public and each other about their services (Shaw et al. 2011). In addition, providers can recognize that the availability of funds, according to Provan and Milward (1995), and Miller (1980), is not directly linked to positive system outcomes, but system level factors such as integration are more important in the provision of care services. The existing networks of the five Central American countries included in this study demonstrate that the exchange of resources counters lack of funding and fosters collaboration, which in turn leads to positive system outcomes such as the provision of the care services discovered in this region. For example, in all five countries, compulsory university student social hours provide necessary health professional services at no cost. Another example from El Salvador, is a care home providing an office space to the Alzheimer's association in exchange for training and support to the staff and residents' families. This realization will allow for an appreciation of their cultures of exchange, and can further motivate the development of integration.

Finally, the findings of this study may influence policies on and implementation of partnership working and new inter-organizational practices leading to outcomes of increased system integration and consequently increased provision/receipt of integrated services (Valente et al. 2015). To help policy makers establish priorities for building integration in older adult and dementia care systems, SNA indicators offer the evaluation of organizational relationships within policy contexts. At the whole network level, structural indicators can be compared cross-nationally as well. Thus, the transferability of this study to any context raises the same research questions for other countries. As the integrated care culture spreads and more governments opt for it, the incidence of dementia increases, thus the state of older adult service systems in any country, especially in LMIC, will be under scrutiny (Blanchet and James 2012). In choosing to utilize this study's methodology, the evaluation of the substratum of health and care services, social interactions, can provide insight at the micro, meso and macro levels (Blanchet and James 2012, 2013). Key policy integration indicators can be provided, by the methodological framework of this study, for evaluating possible gaps in care service provision systems. Finally, the design of context based interventions supporting cooperation is streamlined through this type of evaluation (Kwait 2001).

## Limitations

Methodological limitations were relative to potential biases. This study allows network participants a vision of the organizations, their connections and their roles. However, it is a cross-sectional vision. Considering the fluid nature of networks, only a regular assessment can portray the development of system integration and effectiveness (Wang et al. 2016). In addition, one representative of each organization was interviewed, precluding any ties between other employees and organizations. In addition, ties were established via one organization's claim, where possible the claims were verified, but not all organizations nominated were interviewed due to time and resource constraints. Lastly, the sampling methods used, snowball and reputational, neglect organizations that are completely independent of the networks, not connected to any of the other organizations. The inconsistency of the quality of fieldwork is another limitation. Progressive researcher fatigue, availability and willingness of providers to participate, and the magnitude of the study comprising of five countries, may have influenced the inclusion or exclusion of service providers in the networks. Having the possibility to have taken breaks between countries could have prevented researcher fatigue, possibly leading to more inclusive samples. In general, being a 'foreign researcher' turned out to be a facilitating factor, creating a sense of excitement and gratitude from interviewees for the interest in their country, and how their system operated. This makes a case encouraging more research in Central America.

## Further Research

In terms of further research, a longitudinal investigation of these systems would provide data on the implementation and development of integration (Wang et al. 2016, Glasby and Dickinson 2014, Davis et al. 2012, Blanchet and James 2012). The effectiveness of these networks should also be addressed (Provan and Milward 1995, Provan et al. 2007) to understand if the chosen purposes of each network are achieved (van Raak and Paulus 2001, Suter et al. 2009). Effectiveness relates to the outcomes of implementing formal alliances, as

suggested, and how these will affect the ties and exchanges, as well as the role that government agencies play in shaping the ties and the exchanges, and influencing formal alliances (Provan et al. 2007). Still related to effectiveness, research on cliques, or groups of ties, within networks, and the relation these have to network outcomes could be considered for further research (Provan and Sebastian 1998).

More research needs to focus on families with dementia. The family interviews of this study focused on the organizational structure of the system, not individual needs. Research concentrating on the micro level, the perspectives of families with dementia, would provide deeper insight into the mechanisms of the service systems (Portacolone et al. 2014), and consequently highlight what factors impede them from having more central positions in the networks (Gajardo et al. 2017, Broda et al. 2017, Bieber 2019).

## Conclusion

The main contribution of this study is the investigation of previously unknown older adult and dementia service systems in an under researched region. This research pioneers with primary data of older adult and dementia services in five Central American countries that are missing in the current literature. Additionally, this study pioneers by using an innovative methodology to uncover information that is unknown in most countries, about the substructures of the specific older adult and dementia health service systems

My findings indicate that the five countries have similar, multidisciplinary and multisectoral systems with some unique elements. The systems are framed by national older adult protection policies, but four countries need yet to develop dementia specific plans. The inter-organizational exchanges of resources and multiplex exchanges were found to be pervasive, presenting an established method of maintaining the systems, to counter the lack of funding common in the region. Although the foundations for developing system integration were present, based on strong and collaborative ties and exchange, an overall low level of integration was assessed for each country due to very low density and

inconsistent coordination. Findings also confirm the disconnection to services perceived by families with dementia, as they were barely linked into the networks.

This study demonstrates how levels of integration relate to a system's capacity to provide a biopsychosocial model of care. To proceed with the development of integration, I have outlined next steps each country can take, beginning with a collective decision to cooperate in a structured fashion by means of shared goals. I have also delineated key messages for service providers, policy makers, and researchers, which could contribute to integration implementation.

This study contributes methodologically and practically by making a valuable and new mapping of population based health systems, and their substructures, through the interactions between service providers. This mapping demonstrates the utility of social network analysis in researching and evaluating the current needs and gaps of dementia care service systems both in and between countries (Hallberg et al. 2013).

With hindsight, comparing five countries was very ambitious and possibly excessive for a single, self-funded, PhD. The 10 months of travel were expensive, and I would not replicate this sort of project without funding. The most arduous challenges proved to be data organization and analysis, where the amount of data limited an extensive analysis of every aspect. The assimilation and adaptation cycles I underwent in each country, summed with the constant anxiety of the possibility of aggression and violence, culminated in depression like symptoms that I had not recognized, nor expected. Notwithstanding, this project culminated in a life journey that reaffirmed my faith in humanity through the many passionate and capable people I met that stand up for quality of care and defend the rights of those more vulnerable.

## References

Acosta, M., Sáenz, MR., Gutiérrez, B., Bermúdez, JL., (2011). Sistema de salud de El Salvador. *Salud Publica de Mexico*. Vol.53(2), p188-196.

Adams, W. (2015). Conducting Semi-Structured Interviews. In W. Adams, *Handbook of Practical Program Evaluation: Fourth Edition* (pp. 492-505). Wiley Blackwell.

Ahgren, B., (2012). The Art of Integrating Care: Theories Revisited. *The Open Public Health Journal*. Vol.5, p36-39.

Alzheimer Europe. (2014). *Policy in Practice*. Available: <https://www.alzheimer-europe.org/Policy-in-Practice2> [Accessed 11-1-19].

Alzheimer Europe. (2015). Paris Declaration 2006. Available: <https://www.alzheimer-europe.org/Policy-in-Practice2/Paris-Declaration> [Accessed 19-5-19].

Alzheimer Europe. (2017). *Glasgow Declaration 2014*. Available: <https://www.alzheimer-europe.org/Policy-in-Practice2/Glasgow-Declaration> [Accessed 19-5-19].

Alzheimer Europe. (2019). *European Working Group of People with Dementia - EWGPWD*. Available: <https://www.alzheimer-europe.org/Alzheimer-Europe/Who-we-are/European-Working-Group-of-People-with-Dementia> [Accessed 21-2-20].

Alzheimer Europe. (2019). *G20 places dementia prominently on its agenda*. Available: <https://www.alzheimer-europe.org/News/Policy-watch/Saturday-29-June-2019-G20-places-dementia-prominently-on-its-agenda> [Accessed 15-1-20].

Alzheimer Ibero America. (2019). Available: <https://alzheimeriberoamerica.org> [Accessed 16-1-20].

Alzheimer's Disease International. (2020). *Dementia Plans*. Available: <https://www.alz.co.uk/dementia-plans> [Accessed 12-2-20].

Alzheimer's Disease International. (2020). *World Health Organization*. Available: <https://www.alz.co.uk/world-health-organization> [Accessed 12-2-20].

Alzheimer's Disease International, (2011). *UN Summit recognises dementia importance*. Available at: <https://www.alz.co.uk/news/united-nations-summit-recognises-dementia-importance> [Accessed 22-10-19].

Alzheimer's Disease International. (2018). *From plan to impact: Progress towards targets of the global action plan on dementia*. London. p1-22.

Alzheimer's Disease International. (2018). *Global action plan on the public health response to dementia*. London. p1-42

- Alzheimer's Society, (2017). *Risk Factors and Prevention*. Available at: [https://www.alzheimers.org.uk/info/20010/risk factors and prevention](https://www.alzheimers.org.uk/info/20010/risk_factors_and_prevention) [Accessed 17-10-19].
- Americacentral. (2019). Available: <http://www.americacentral.info> [Accessed 26-3-20].
- Archer, M., Decoteau, C., Gorski, P., Little, D., Porpora, D., Rutzou, T., Smith, C., Steinmetz, G., Vandenberghe, F. (2016). What is critical realism? *Perspectives: A Newsletter Of The ASA Theory Section*. American Sociological Association. <http://www.asatheory.org/current-newsletter-online/what-is-critical-realism> [Accessed 4-9-19].
- Axelsson, R. and Axelsson, S. B., (2006). Integration and collaboration in public health--a conceptual framework. *The International journal of health planning and management*. Vol.21(1), p75-88.
- Baistow, K., (2000). Cross-national Research: What Can We Learn from Inter-country Comparisons? *Social Work in Europe*. Vol.7(3), p8-13.
- Bandyopadhyay, S., Rao, A. R., Sinha, B. K., (2011). Introduction to Social Network Analysis. In: *Models for social networks with statistical applications*. SAGE, p1-29.
- Barbarino, P., Lynch, C., Bliss, A., Dabas, L. (2019). *From Plan to Impact II: The urgent need for action*. Alzheimer's Disease International. London. p1-62.
- Barnes, R., Auburn, T., Lea, S., (2004). Citizenship in practice. *British Journal of Social Psychology*. Vol.6,43(2), p187-206.
- Barnes, S. and Design in Caring Environments Study Group. (2002). The design of caring environments and the quality of life of older people. *Ageing and Society*. Vol.22(6), p775-789.
- Barnett, G. (2011). *Encyclopedia of social networks*. Thousand Oaks: Sage Publications.
- Barrett, B., (1996). Integrated local health systems in Central America. *Social Science & Medicine*. Vol.43(1), p71–82.
- Bartlett, R. and O'Connor, D., (2007). From personhood to citizenship: Broadening the lens for dementia practice and research. *Journal of Aging Studies*. Vol.4, 21(2), p107-118.
- Bate, P. (2014). Context is everything. In: J.R. Bamber. *Perspectives on Context*. The Health Foundation. London.
- Beáta, D., (2013). Social network analysis: Applied tool to enhance effective collaboration between child protection organisations by Revealing and strengthening Work relationships. *European Journal of Mental Health*. Vol.8(1), p3-28.

- Becerril-Montekio, V. and López-Dávila, L. (2011). Sistema de salud de Guatemala. *Salud Publica de Mexico*. Vol.53(2), p197-208.
- Bell, V. and Troxel, D. (1996). *The best friends approach to Alzheimer's care*. Baltimore. Health Professions Press.
- Bermúdez-Madriz, J.L., Sáenz, M.R., Muiser, J., Acosta, M. (2011). Sistema de salud de Honduras. *Salud Publica de Mexico*. Vol. 53(2), p209-219.
- Bieber, A., Nguyen, N., Meyer, G., Stephan, A., (2019). Influences on the access to and use of formal community care by people with dementia and their informal caregivers: A scoping review. *BMC Health Services Research*. Vol.19(1), p1-21.
- Binns, T. (2006). Doing Fieldwork in Developing Countries: Planning and Logistics. In: V. Desai & R. Potter, eds. *Doing development research*. London: Sage Publications, p13-24.
- Blanchet, K. and James, P., (2012). How to do (or not to do) ... a social network analysis in health systems research. *Health Policy and Planning*. Vol.27(5), p438-446.
- Blanchet, K. and James, P., (2013). The role of social networks in the governance of health systems: The case of eye care systems in Ghana. *Health Policy and Planning*, Vol.28(2), p143-156.
- Blau, P. (1964). Justice in Social Exchange. *Sociological Inquiry*, Vol.34(2), p193-206.
- Block, M. and McQuire, S. (2008). Health systems of Mexico, Central America and the Caribbean. In M. Block, & S. McQuire, *International Encyclopedia of Public Health* p256-265.
- Bloom, G., Standing, H., (2008). Future health systems: Why future? Why now? *Social Science & Medicine*, Vol.66(10), p2067-2075.
- Bluestone, K., Escribano, J., Horstead, K., Mikkonen-Jeanneret, E., Rossal, P. (2015). Facing the facts: The truth about ageing and development. Age International. London. p1-88.
- Bond, J., (1992). The medicalization of dementia. *Journal of Aging Studies*, Vol.6(4), p397-403.
- Booth, J. (2010). *Understanding Central America: Global Forces, Rebellion, and Change*. 5th edition. Boulder: Westview Press.
- Borgatti, S. (2020). *SNA Resources*. Retrieved from Google Sites: <https://sites.google.com/site/snareources/home> [Accessed 5-3-20]
- Borgatti, S., Mehra, A., Brass, D. & Labianca, G., (2009). Network analysis in the social sciences. *Science*. Vol.323(October 2016), p892-895.
- Borgatti, S.P., Everett, M.G., Freeman, L.C. (2002). *Ucinet for Windows: Software for social network analysis*. Harvard, MA: analytic technologies.



- Borrell-Carrio, F., Suchman, A., Epstein, R., (2004). The Biopsychosocial Model 25 Years Later. *Annals of Family Medicine*. Vol.2(6), p576–582.
- Braun, V., and Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, Vol.3(2), p77-101.
- Brito-Aguilar, R. (2019). Dementia Around the World and the Latin America and Mexican Scenarios. *Journal of Alzheimers Disease*. Vol.7(1), p1-5.
- Broda, A., Bieber, A., Meyer, G., Hopper, L., Joyce, R., Irving, K., Zanetti, O., Portolani, E., Kerpershoek, L., Verhey, F., Vugt, M., Wolfs, C., Eriksen, S., Røsvik, J., Marques, M., Gonçalves-Pereira, M., Sjölund, B., Woods, B., Jelley, H., Orrell, M. and Stephan, A. (2017). Perspectives of policy and political decision makers on access to formal dementia care: expert interviews in eight European countries. *BMC Health Services Research*. Vol.17(1), p1-14.
- Brofenbrenner, U. (1977). Toward an Experimental Ecology of Human Development. *American Psychologist*, Vol.32(7), p513-531.
- Brooker, D. (2003). What is Person-Centred Care in Dementia? *Reviews in Clinical Gerontology*. Vol.13(3), p215–222.
- Browne, G., Kingston, D., Grdisa, V., Markle-Reid, M. (2007). Conceptualization and measurement of integrated human service networks for evaluation. *International journal of integrated care*. Vol.7(December), p1-6.
- Buch-Hansen, H. (2014). Social network analysis and critical realism. *Journal for the Theory of Social Behaviour*. Vol.44(3), p306-325.
- Bunger, A. C., Doogan, N. J., Cao, Y. (2014). Building Service Delivery Networks: Partnership Evolution Among Children's Behavioral Health Agencies in Response to New Funding. *Journal of the Society for Social Work and Research*. Vol.5(4), p513-538.
- Bunn, F., Burn, A., Robinson, L., Poole, M., Rait, G., Brayne, C., Schoeman, J., Norton, S., Goodman, C. (2017). Healthcare organisation and delivery for people with dementia and comorbidity: a qualitative study exploring the views of patients, carers and professionals. *BMJ Open*. Vol.7(1), p1-9.
- Bunn, F., Burn, A., Goodman, C., Rait, G., Norton, S., Robinson, L., Schoeman, J., Brayne, C. (2014). Comorbidity and dementia: a scoping review of the literature. *BMC Medicine*. Vol.12(1), p173-177.
- Burns, A. and Buckman, L. (2013). *Timely diagnosis of dementia: Integrating Perspectives, Achieving Consensus*. Timely Diagnosis of Dementia Consensus Group. NHS England.
- Butler, M., Kickbusch, I., Sousa-Posa, A. (2008). *The Madrid International Plan of Action on Ageing: Where Are We Five Years Later?* Madrid. United Nations Population Fund. p1-151.

- Cacace, M., Ettelt, S., Mays, N., Nolte, E. (2013). Assessing quality in cross-country comparisons of health systems and policies: Towards a set of generic quality criteria. *Health Policy*. Vol.9, 112(1-2), p.156-162.
- Carr, T.J., Hicks-Moore, S., Montgomery, P. (2011). What's so big about the 'little things': A phenomenological inquiry into the meaning of spiritual care in dementia. *Dementia*. Vol.10(3), p399-414.
- Cruz, J. M., (2015). The Root Causes of the Central American Crisis. *Current History*. Vol.114(769), p42–48.
- Cullell, J.V. (2012). Advancing the Study of Stateness in Central America: Methodology and Some Illustrative Findings. *Revista de Ciencia Política*. Vol.32(3), p703–722.
- Dam, A., De Vugt, M., Klinkenberg, I., Verhey, F., Van Boxtel, M. (2016). A systematic review of social support interventions for caregivers of people with dementia: Are they doing what they promise? *Maturitas*. Vol.85, p117-130.
- David, S. (2007). Resolving the quantitative-qualitative dilemma: a critical realist approach. *International Journal of Research & Method in Education*. Vol.30(1), p3-17.
- Davies, C. (2002). *What is 'Hispanic Studies'? The Companion to Hispanic Studies*. London. Oxford University Press.
- Davis, M., Koroloff, N., Johnsen, M. (2012). Social network analysis of child and adult interorganisational connections. *Psychiatric Rehabilitation Journal*. Vol.35(3), p265-272.
- de Carvalho, I., Epping-Jordan, J., Pot, A., Kelley, E., Toro, N., Thiyagarajan, J., Beard, J. (2017). Organizing integrated health-care services to meet older people's needs. *Bulletin of the World Health Organization*. Vol.95(11), p756-763.
- de Nooy, W., Mrvar, A., Batagelj, V. (2018). *Exploratory Social Network Analysis with Pajek*. Revised and Expanded Edition for Updated Software. Third Edition. New York: Cambridge University Press.
- De Redacción, C. (2015). Una revisión de los escenarios actuales de América Latina. *Revista de Fomento Social*. Vol.70, p143–172.
- de Sola Pool, I. and Kochen, M. (1978). Contacts and influence. *Social Networks*, Vol.1(1), p5-51.
- Dementia Alliance International, (2014). About DAI. Available at: <http://www.dementiaallianceinternational.org/> [Accessed 3-2-20]
- Dementia Alliance International, (2016). *The Human Rights of People Living with Dementia: from Rhetoric to Reality*. London.
- Dewing, J. (2007). Participatory research: A method for process consent with persons who have dementia. *Dementia*. Vol. 6(1), p11-25.

- Dewing, J. (2008). Personhood and dementia: revisiting Tom Kitwood's ideas. *International Journal of Older People Nursing*, Vol.3(1), p3-13.
- Donabedian, A. (1966). Evaluating the Quality of Medical Care. *The Milbank Memorial Fund Quarterly*. Vol.44,(3), p166–203.
- Donabedian, A., (1997). The quality of care. How can it be assessed? *JAMA: The Journal of the American Medical Association*, Vol.260(12), p1743-1748.
- Dong, X. Simon, M.A., Gorbien, M. (2008). Elder Abuse and Neglect in an Urban Chinese Population. *Journal of Elder Abuse and Neglect*. Vol.19(3-4), p79-96.
- Dorenlot, P. (2005). Editorial: Applying the social model of disability to dementia: present-day challenges. *Dementia*. Vol.4(4), p459-461.
- Downs, M, and Bowers, B. (2014). *Excellence In Dementia Care: Research Into Practice*. 2nd edition. Maidenhead. McGraw-Hill Education, Milton Keynes.
- Downs, M. and Bowers, B. (2010). Excellence in dementia care: research into practice. *International Journal of Integrated Care*. Vol.10(September) p1-2.
- Doyle, P. J. and Rubinstein, R. L., (2013). Person-Centred Dementia Care and the Cultural Matrix of Othering. *The Gerontologist*. Vol.54(6), p952–963.
- Dunn, A. G. and Westbrook, J. I., (2011). Interpreting social network metrics in healthcare organisations: A review and guide to validating small networks. *Social Science and Medicine*. Vol.72(7), p1064-1068.
- Edvardsson, D. and Innes, A. (2010). Measuring Person-centred Care: A Critical Comparative Review of Published Tools. *The Gerontologist*. Vol.50(6), p834-846.
- Elder, J. W. (1976). Comparative Cross-National Methodology. *Annual Review of Sociology*, pp. 209-230.
- Emerson, R. M., (1976). Social Exchange Theory. *Annual Review of Sociology*. Vol.2, p335-362.
- Engel, G. (1977). The Need for a New Medical Model: A Challenge for Biomedicine. American Association for the Advancement of Science Stable. *Science, New Series*. Vol.196(4286), p129–136.
- Engel, G.L. (1981). George I. Engel the clinical application of the biopsychosocial model. *The Journal of Medicine and Philosophy*. Vol.6, p101–123.
- Engel, G.L., (1997). From biomedical to biopsychosocial. Being scientific in the human domain. *Psychosomatics*. Vol.38(6), p521–8.
- Engel, P.A., (2001). George L. Engel, M.D., 1913-1999: remembering his life and work; rediscovering his soul. *Psychosomatics*. Vol.42(2), p94–9.
- Epp, T. D., (2003). Person-centred Dementia Care: A Vision to be Refined. *The Canadian Alzheimer Disease Review*. Issue April, p14-18.

- Federación Iberoamericana de Asociaciones de Personas Adultas Mayores. (2020). Available: <https://fiapam.org/quienes-somos/fines-y-objetivos/> [Accessed 23-2-20]
- Feil, N. (1982). Group Work with Disoriented Nursing Home Residents. *Social Work with Groups*. Vol.5(2), p57-66.
- Ferri, C. P. and Jacob, K. S. (2017). Dementia in low-income and middle-income countries: Different realities mandate tailored solutions. *PLoS Medicine*. Vol.14(3), p1-4.
- Ferriani, S., Fonti, F., Corrado, R. (2012). The social and economic bases of network multiplexity: Exploring the emergence of multiplex ties. *Strategic Organization*. Vol.11(1), p7-34.
- Finkelstein, V. (1980). Attitudes and disabled people. *Developmental medicine and child neurology*. Vol. 22(4), p427-428.
- Finkelstein, V. (1993). The commonality of disability. In: Swain, J., Finkelstein, V., French, S., Oliver, M., *Disabling barriers, enabling environments*. London. Sage Publications. p9-16.
- Finkelstein, V. (2007). The 'Social Model of Disability' and the Disability Movement. *Greater Manchester Coalition of Disabled People*. Issue August, p1-15.
- Fitzgerald, M. and McLoughlin, P. (2016). *Dementia Specific Services in the Community: Mapping Public and Voluntary Services*. The Alzheimer Society of Ireland, National Dementia Office in the Health Service, Ireland.
- Foa, E. and Foa, U. (2012). Resource Theory of Social Exchange. In Foa, E., Foa, U., Törnblom, K., Kazemi, A. (Eds.), *Handbook of social resource theory: Theoretical extensions, empirical insights, and social applications*. New York, NY, US: Springer Science and Business Media. p15-32.
- Formiga, F., Fort, I., Robles, M., Riu, S., Sabartes, O., Barranco, E., & Catena, J. (2009). Comorbidity and clinical features in elderly patients with dementia: Differences according to dementia severity. *Journal of Nutrition, Health and Aging*, 13(5), 423-427.
- Fox, C., Maidment, I., Moniz-Cook, E., White, J., Thyrian, J.R., Young, J., Katona, C., Chew-Graham, C. (2013). Optimising primary care for people with dementia. *Mental Health Family Medicine*. Vol.10(3), p143–151.
- Fox, C., Lafortune, L., Boustani, M., Brayne, C. (2013). The pros and cons of early diagnosis in dementia. *British Journal of General Practice*. July, p510-511.
- Fox, R. (2004) A Perpetual Fieldworker. *Annals of the American academy of political and social science*. Issue 595, p309-326.
- Frankl, V., (1984). *Man's Search for Meaning*. Washington Square Press.

- Freeman, L. C., (1978). Centrality in social networks conceptual clarification. *Social Networks*. Vol.1(3), p215-239.
- Fried, B., Johnsen, M., Starrett, B., Calloway, M., Morrissey, J. (1998). An Empirical Assessment of Rural Community Support Networks for Individuals with Severe Mental Disorders. *Community Mental Health Journal*, Vol. 34(1), p40-56.
- Fulk, J. (2001). Global Network Organizations: Emergence and Future Prospects. *Human Relations*, 54(200101), pp. 91-99.
- G20. (2019). *Osaka Leaders' Declaration*. Osaka. pp 1-13.  
<https://www.consilium.europa.eu/en/press/press-releases/2019/06/29/g20-osaka-leaders-declaration/> [Accessed 2-12-20]
- Gajardo, J., Aravena, J., Budinich, M., Larraín, A., Fuentes, P., Gitlin, L. (2020). The Kintun program for families with dementia: From novel experiment to national policy (innovative practice). *Dementia*. Vol.19(2), p488-495.
- Gallelli, A. (2016) Social Structure and Cultural Production: An Empirical Analysis of Festivals' Networks. *The Journal of Arts Management, Law, and Society*. Vol.46(1), p34-46.
- Gatchel, R., Peng, Y., Peters, M., Fuchs, P., Turk, D. (2007). The Biopsychosocial Approach to Chronic Pain: Scientific Advances and Future Directions. *Psychological Bulletin*. Vol.133(4), p581–624.
- Gaugler, J., Bain, L., Mitchell, L., Finlay, J., Fazio, S., Jutkowitz, E., Zimmerman, S. (2019). Reconsidering frameworks of Alzheimer's dementia when assessing psychosocial outcomes. *Alzheimer's and Dementia: Translational Research and Clinical Interventions*. Vol.5, p388-397.
- Giedion, U., Villar, M., Ávila, A. (2010). *Los sistemas de salud en Latinoamérica y el papel del seguro privado*. Publisher: Fundación MAPFRE.
- Gilliard, J., (2005). Dementia care in England and the social model of disability: Lessons and issues. *Dementia*. Vol.4(4), p571-586.
- Glasby, J., and Dickinson, H. (2014). *Partnership Working In Health and Social Care*. 2nd Edition. London: Policy Press.
- Goedert, M., (2009). Oskar Fischer and the study of dementia. *Brain: A Journal of Neurology*. Vol.132, p1102–1111.
- Goldstein-Levitas, N., (2016). Dance/Movement Therapy and Sensory Stimulation: A Holistic Approach to Dementia Care. *American Journal of Dance Therapy*. Vol.38(2), p429-436.
- Gonzalez, F., Gaona, C., Quintero, M., Chavez, C., Selga, J., Maestre, G. (2014). Building capacity for dementia care in Latin America and the Caribbean. *Dementia & Neuropsychologia*. Vol.8(4) p310-316.

- Gould, N., (2011). Guidelines across the health and social care divides: The example of the NICE-SCIE dementia guideline. *International Review of Psychiatry*. Vol. August, p365–370.
- Gouldner, A. W., (1960). The Norm of Reciprocity: A Preliminary Statement. *American Sociological Review*. Vol.25(2) p161-178.
- Granovetter, M., (1973). The Strength of Weak Ties. *The American Journal of Sociology*. Vol.78(6), p1360-1380.
- Guarini Institute. (2002). *Briefing on Third World Assembly on Ageing*. pp: 1-9. <https://www.un.org/development/desa/ageing/> [Accessed 19-2-20]
- Guba, E.G., Lincoln, Y.S. (1994). Competing paradigms in qualitative research. In Denzin, N.K., Lincoln, Y.S. *Handbook of qualitative research*. Thousand Oaks. Sage. p105-117.
- Hallberg, I., Leino-Kilpi, H., Meyer, G., Raamat, K., Martin, M., Sutcliffe, C., Karlsson, S. (2013). Dementia Care in Eight European Countries: Developing a Mapping System to Explore Systems. *Journal of Nursing Scholarship*. Vol.45(4), p412–424.
- Ham, C. and Curry, N. (2011). *Integrated care: What is it? Does it work? What does it mean for the NHS?* London. The King's Fund. pp 1-8.
- Hanneman, R. & Riddle, M., (2019). *Some Statistical Tools*. In: *Introduction to Social Network Methods*. Riverside: Open Education Resource (OER) LibreTexts Project. Vol.18(3), p1-5.
- Hanneman, Robert A. and Mark Riddle. (2005). *Introduction to social network methods*. Riverside, CA: University of California, Riverside. Published in digital form <http://faculty.ucr.edu/~hanneman>
- Hanneman, Robert, A. & Riddle, M., (2011). A Brief Introduction to Analyzing Social Network Data. In: *The SAGE Handbook of Social Network Analysis*. SAGE Publications, p331-339.
- Hanneman, Robert, A. & Riddle, M., (2011). Concepts and Measures for Basic Network Analysis. In: P. J. Carrington & J. Scott, eds. *The SAGE Handbook of Social Network Analysis*. SAGE Publications, p340-622.
- Hantrais, L. (1995). *Comparative Research Methods*. Available at: <http://sru.soc.surrey.ac.uk/SRU13.html> [Accessed 13-1-20]
- Hantrais, L., (2009). *International Comparative Research*. London: Palgrave Macmillan.
- Harnett, P. J., Kennelly, S., Williams, P. (2019). A 10 Step Framework to Implement Integrated Care for Older Persons. *Ageing International*. Vol.26(6), p1-17.
- Hasnain-Wynia, R., Sofaer, S., Bazzoli, G., Alexander, J., Shortell, S., Conrad, D., Chan, B., Zukoski, A., Sweney, J. (2003). Members' Perceptions of Community

Care Network Partnerships' Effectiveness. *Medical Care Research and Review*. Vol.60(4), p40-62.

Hausman, A. (2001). Variations in relationship strength and its impact on performance and satisfaction in business relationships. *Journal of Business & Industrial Marketing*. Vol.16(7), p600-616.

Hawe, P., Webster, C., Shiell, A. (2004). A glossary of terms for navigating the field of social network analysis. *Journal of epidemiology and community health*. Vol.58(12), p971-5.

Hébert, R. and Veil, A. (2004). Monitoring the degree of implementation of an integrated delivery system. *International Journal of Integrated Care*. Vol.4(3), pNone.

Heckman, G., Crutchlow, L., Boscart, V., Hillier, L., Franco, B., Lee, L., Molnar, F., Seitz, D., Stolee, P. (2019). Quality assurance as a foundational element for an integrated system of dementia care: Perspectives from Physicians and Geriatricians. *International Journal of Health Care Quality Assurance*, Vol.32(6), p978-990.

Higgs, P. & Gilleard, C., (2016). Interrogating personhood and dementia. *Aging and Mental Health*. Vol.20(8), p773-780.

Hoe, C., Adhikari, B., Glandon, D., Das, A., Kaur, N., (2019). Using social network analysis to plan, promote and monitor intersectoral collaboration for health in rural India. *PLoS One*. Vol.14(7), e0219786.

Hossain, L. (2009). Effect of organisational position and network centrality on project coordination. *International Journal of Project Management*. Vol.10, 27(7), p680-689.

Houston, S. (2001). Beyond Social Constructionism: Critical Realism and Social Work. *British Journal of Social Work*. Vol: 31 p845-861.

Hsiao, Y., Kuo, T., Tai, C., Lee, S., Lee, M. (2019). Integrated care for dementia in Taiwan: Policy, system and services. *International Journal of Gerontology*, Special Issue, pS73-S77.

Huenchuan, S. (2011). *Legislación comparada sobre personas mayores en Centroamérica y la República Dominicana*. Comisión Económica para América Latina y el Caribe (CEPAL), Santiago de Chile. <https://fiapam.org/wp-content/uploads/2012/10/Comparada.pdf>

Innes, A. (2009). *Dementia Studies: A social science perspective*. London. Sage publications.

Janowitz, M. (1958). Book Review: The Theory of Social Structure, S.F. Nadel. *American Sociological Review*. Vol.23(2), p218-220.

Jasemi, M., Valizadeh, L., Zamanzadeh, V., Keogh, B. (2017). A concept analysis of holistic care by hybrid model. *Indian Journal of Palliative Care*. Vol.23(1), p71.

- Jelley, H., Kerpershoek, L., Verhey, F., Wolfs, C., de Vugt, M., Bieber, A., Stephan, A., Meyer, G., Michelet, M., Selbaek, G., Sjölund, B., Sköldunger, A., Hopper, L., Irving, K., Marques, M., Balsinha, M., Gonçalves-Pereira, M., Portolani, D., Zanetti, O. and Woods, B. (2019). Carers' experiences of timely access to and use of dementia care services in eight European countries. *Ageing and Society*. p1-18.
- Johansson, L., Guerra, M., Prince, M., Hördler, H., Falk, H., Stubbs, B., Prina, A., (2019). Associations between Depression, Depressive Symptoms, and Incidence of Dementia in Latin America: A 10/66 Dementia Research Group Study. *Journal of Alzheimer's Disease*. Vol.69(2), p433-441.
- Jolley, D. & Moreland, N. (2011). Dementia care: spiritual and faith perspectives. *Nursing & Residential Care*. Vol.13(8), p388-392.
- Jones, K. (2014). Calls intensify for national dementia plan. *CMAJ: Canadian Medical Association Journal*. Vol.186(2), p97.
- Kalaria, R., Maestre, G., Arizaga, R., Friedland, R., Galasko, D., Hall, K., Luchsinger, J., Ogunniyi, A., Perry, E., Potocnik, F., Prince, M., Stewart, R., Wimo, A., Zhang, Z., Antuono, P. (2008). Alzheimer's disease and vascular dementia in developing countries: prevalence, management, and risk factors. *The Lancet Neurology*. Vol.7(9), p812-826.
- Keady, J. et al., (2012). Introducing the bio-psycho-social-physical model of dementia through a collective case study design. *Journal of Clinical Nursing*, Volume 22, pp. 2768-2777.
- Keady, J., Jones, L., Ward, R., Koch, S., Swarbrick, C., Hellström, I., Davies-Quarrell, V., Williams, S. (2012). Introducing the bio-psycho-social-physical model of dementia through a collective case study design. *Journal of Clinical Nursing*. Vol.22(19-20), p2768-2777.
- Kellehear, A. (2009). Dementia and dying: The need for a systematic policy approach Is there a need for a systematic approach. *Critical Social Policy*. Vol.29(1) p146-157.
- Kelley, F. (2010). Decision-Making, Personhood and Dementia: Exploring the Interface. *Health and Social Care*. Vol.18(5), p549-550.
- Kinnaird, L. (2012). *Delivering Integrated Dementia Care: The 8 Pillars Model of Community Support*, Edinburgh.
- Kitwood, T. and Bredin, K. (1992). Towards a Theory of Dementia Care: Personhood and Well-being. *Ageing and Society*. Vol.12(3), p269-287.
- Kitwood, T. (1993). Towards a Theory of Dementia Care: The Interpersonal Process. *Ageing and Society*. Vol.13(1), p51-67.
- Knapp, M., Comas-Herrera, A., Somani, A. Banerjee, S. (2007). *Dementia: international comparisons*. London. National Audit Service. p1-20.  
<http://eprints.lse.ac.uk/3353/> [Accessed 22-11-19]



- Knoke, D. and Yang, S., (2008). *Social Network Analysis*. Second ed. SAGE Publications.
- Knoke, D. and Yang, S., (2011). Data Collection. In: *Social Network Analysis*. SAGE Publications, p103-125.
- Kodner, D. L. and Spreeuwenberg, C., (2002). Integrated care: meaning, logic, applications, and implications--a discussion paper. *International journal of integrated care*. Vol.2(November), pe12.
- Kothari, C. (2004). *Research Methodology: Methods and Techniques*. 2nd ed. United States: New Age International Pvt. Ltd. ProQuest Ebook Central.
- Krackhardt, D. and Stern, R. N. (1988). Informal Networks and Organizational Crises: An Experimental Simulation. *Social Psychology Quarterly*. Vol.51(2), p123-140.
- Kümpers, S. (2005). *Steering integrated care in England and The Netherlands: The case of dementia care: A neo-institutionalist comparative study*. Department of Health Organisation, Policy and Economics of Maastricht University.
- Kurtenbach, S. (2019) Latin America-Multilateralism without Multilateral Values. *IGA Working Papers*, No. 7, German Institute of Global and Area Studies (GIGA), Hamburg.
- Kurtenbach, S., (2007). Why Is Liberal Peace-building. So Difficult? Some Lessons from Central America. *IGA Working Papers*, No. 59, German Institute of Global and Area Studies (GIGA), Hamburg.
- Kwait, J., Valente, D.T.W., Celentano, D. D. (2001). Interorganisational relationships among HIV/AIDS service organizations in Baltimore: A newtwork analysis. *Journal of Urban Health*. Vol.78(3), p468-487.
- Lachs, M. and Pillemer, K. (2004). Elder Abuse. *The Lancet*. Vol.364(9441) p1263-1272.
- Lawrence, P. and Lorsch, J. (1967). Differentiation and Integration in Complex Organizations. *Administrative Science Quarterly*. Vol.12, p1-47.
- Lawson, C. (2007). Technology, technological determinism and the transformational model of social activity. In *Contributions to Social Ontology*. Oxon. Routledge. p32-49.
- Lawson, C., Latsis, J., Martins, N. O., (2007). *Contributions to Social Ontology*. Oxon: Routledge.
- Lawton, M.P. and Nahemow, L. (1973). Ecology and the aging process. In C. Eisdorfer and M.P. Lawton (Eds.), *The psychology of adult development and aging*. American Psychological Association. p619–674.
- Lawton. P.M. (1972). Social Ecology and the Health of Older People. *American Journal of Public Health*. Vol.64(3), p257-260.

- Leavitt, H. J. (1951). Some effects of certain communication patterns on group performance. *The Journal of Abnormal and Social Psychology*. Vol.46(1), p38-50.
- Leijten, F., Struckmann, V., van Ginneken, E., Czypionka, T., Kraus, M., Reiss, M., Tsiachristas, A., Boland, M., de Bont, A., Bal, R., Busse, R., Rutten-van Mólken, M. (2018). The SELFIE framework for integrated care for multi-morbidity: Development and description. *Health Policy*. Vol.122(1), p12-22.
- Leutz, W. (1976). The informal community caregiver: a link between the health care system and local residents. *American Journal of Orthopsychiatry*. Vol.46(4), p678-688.
- Leutz, W. N., 1999. Five laws for integrating medical and social services: lessons from the United States and the United Kingdom. *The Milbank quarterly*. Vol.77(1), p77-110, iv-v.
- Lo Brutto, G. and Vázquez Salazar, C. (2015). The Strategic Integration of Latin America: A Disputed Project. *Latin American Perspectives*. Vol.42(4), p61-72.
- Macadam, M. (2008). *Frameworks of Integrated Care for the Elderly: A Systematic Review*. CPRN Research Report. Ottawa. Canadian Policy Research Networks. p1-35. <http://www.integrationresources.ca/resources/frameworks-of-integrated-care-for-the-elderly-a-systematic-review/> [Accessed 22-11-19]
- Manes, F. (2016). The huge burden of dementia in Latin America. *The Lancet Neurology*. Vol.15(1), p29.
- Marin, A. and Wellman, B. (2011). Social Network Analysis: An Introduction. In: J. Scott & P. Carrington, eds. *The SAGE Handbook of Social Network Analysis*. SAGE Publications, p11-25.
- Marsden, P. V. (2011). Survey Methods for Network Data. In: P. Carrington and J. Scott, eds. *The SAGE Handbook of Social Network Analysis*. SAGE Publications, p370-388.
- McEvoy, L. and Duffy, A., (2008). Holistic practice - A concept analysis. *Nurse Education in Practice*. Vol.8(6), p412-419.
- Mckay, A. S., Grygiel, P., Karwowski, M., (2017). Connected to Create: A Social Network Analysis of Friendship Ties and Creativity. *Psychology of Aesthetics Creativity and the Arts*. Vol.August, p1-11.
- Mehta, J. and Peterson, A. (2019). International learning communities: What happens when leaders seek to learn across national boundaries? *Journal of Educational Change*. Vol.20, p327-350.
- Mental Health Foundation, (2015). Dementia, rights, and the social model of disability. Issue August, p44. <https://www.mentalhealth.org.uk/publications/dementia-rights-and-social-model-disability> [Accessed 8-12-19]
- Miller, J. (1980). Access to Interorganisational Networks as a Professional Resource. *American Sociological Review*. Vol.45(3), p479-496.

- Milte, R., Shulver, W., Killington, M., Bradley, C., Ratcliffe, J., Crotty, M. (2016). Quality in residential care from the perspective of people living with dementia: The importance of personhood. *Archives of Gerontology and Geriatrics*. Vol.63, p9-17.
- Milward, H.B. and Provan, K.G. (1998). Measuring Network Structure. *Public Administration*. Vol.76(2), p387-407.
- Minkman, M., Ligthart, S.A., Huijsman, R. (2009). Integrated dementia care in The Netherlands: a multiple case study of case management programmes. *Health and Social Care in the Community*. Vol.Sep;17(5), p485-94.
- Minkman, M. (2016). The development model for integrated care: A validated tool for evaluation and development. *Journal of Integrated Care*. Vol.24(1), p38-52.
- Mlinac, M. and Feng, M. (2016). Assessment of Activities of Daily Living, Self-Care, and Independence. *Archives of Clinical Neuropsychology*. Vol.31, p506-516.
- Monge, P., Carmenate, L., Piedra, N., Aragón, A., Partanen, T. (2010). Condiciones de salud y trabajo en América Central. *Archivos Prev Riesgos Labor*. Vol.13(2), p84-91.
- Morrissey, J. P. and Calloway, M. (1994). Local Mental Health Authorities and Service System Change: Evidence from the Robert Wood Johnson Program on Chronic Mental Illness. *The Milbank Quarterly*. Vol. 72(1), p49-80.
- Morrissey, J. P., Tausig, M., Lindsey, M. L., (1985). Community Mental Health Delivery Systems. *American Behavioural Scientist*. Vol.28(5), p704-720.
- Nedlund, A.C. and Nordh, J. (2015). Crafting citizen(ship) for people with dementia: How policy narratives at national level in Sweden informed politics of time from 1975 to 2013. *Journal of Aging Studies*. Vol.34, p123–133.
- Nicaise, P., Tulloch, S., Dubois, V., Matanov, A., Priebe, S., Lorant, V. (2013). Using social network analysis for assessing mental health and social services inter-organisational collaboration: Findings in deprived areas in Brussels and London. *Administration and Policy in Mental Health and Mental Health Services Research*. Vol.40(4), p331-339.
- Nies, H. and Berman, P.C. (2004). *Integrating Services for Older People: A resource book for managers*. Dublin: European Health Management Association. p1-223. [www.ehma.org](http://www.ehma.org) [Accessed 24-3-19]
- Noble, T. (2012). Family Breakdown and Social Networks. *The British Journal of Sociology*. Vol.21(2), p135-150.
- Nurjono, M., Valentijn, P., Bautista, M., Wei, L., Vrijhoef, H. (2016). A Prospective Validation Study of a Rainbow Model of Integrated Care Measurement Tool in Singapore. *International Journal of Integrated Care*. Vol.16(1), p1–6.
- Oelke, N., Van Vliet-Brown, C., Suter, E., Dias da Silva Lima, M., Janke, R., Stiphout, M., Hepp, S., Schill, K., Rostami, M., Al-Roubaiai, F., Marck, P., Rigatto Witt, R., Rush, K., Oyedele, O. (2016). Results of a knowledge synthesis

- identifying indicator domains and measures of health system integration. *International Journal of Integrated Care*. Vol.16(6), p283.
- Oliver, M. (1996). *The Social Model in Context*. In: *Understanding Disability*. Palgrave, London.
- Oliver, M. (2013). The social model of disability: thirty years on. *Disability and Society*. Vol.28(7), p1024-1026.
- Oliver, M., (1990). *The Individual and Social Models of Disability*. Paper presented at Joint Workshop of the Living Options Group and the Research Unit of the Royal College of Physicians, Issue July(23), p1-7.
- Organization of American States. (2020). [http://www.oas.org/en/about/who\\_we\\_are.asp](http://www.oas.org/en/about/who_we_are.asp) [Accessed 4-3-20]
- Owen, M. J. and Holmes, C. A., (1993). 'Holism' in the discourse of nursing. *Journal of Advanced Nursing*. Vol.18(11), p1688-1695.
- Page, M. (2007). Client-centred Care for the Person with Dementia: The Essential Spiritual Dimension. *Whitrea Nursing Journal*. Issue 14, p19-25.
- PanAmerican Health Organization. (2015). *Strategy and Plan of Action on Dementias in Older Persons*. Washington D.C. CD54/8, Rev. 1. <https://www.paho.org/en/documents> [Accessed 16-11-19]
- Papageorgiu, I. (2011). Central American integration system. *International Democracy Watch*, Moncalieri. p1-46. <http://www.internationaldemocracywatch.org/index.php/sica> [Accessed 1-12-19]
- Paparella, G. (2016). *Person-centred care in Europe: a cross-country comparison of health system performance, strategies and structures*. Oxford. Policy briefing Picker Institute EuropeOxford. p1-43.
- Parra, M., Baez, S., Allegri, R., Nitrini, R., Lopera, F., Slachevsky, A., Custodio, N., Lira, D., Piguet, O., Kumfor, F., Huepe, D., Cogram, P., Bak, T., Manes, F., Ibanez, A. (2018). Dementia in Latin America. *Neurology*. Vol.90(5), p222-231.
- Pieper, R. (2004). Integrated Organizational Structures. In: H.Nies and P. Berman. *Integrating Services for Older People: A resource book for managers*. Dublin. European Health Management Association. p33-54.
- Plankey-Videla, N. (2012). Informed Consent as Process: Problematizing Informed Consent in Organizational Ethnographies. *Qualitative Sociology*. Vol.35(1), p1-21.
- Portacolone, E., Berridge, C.K., Johnson, J., Schicktanz, S. (2014). Time to reinvent the science of dementia: the need for care and social integration. *Aging & mental health*. Vol.18(3), p.269–75.
- Pot, A. M. and Petrea, I. (2013). *Improving dementia care worldwide: Ideas and advice on developing and implementing a National Dementia Plan*. London. Bupa/ADI.

- Price, L. and Lee, M. (2018). Introduction to the special issue: applied critical realism in the social sciences. *Journal of Critical Realism*. Vol.17(2), p89-96.
- Prina, A. M., Mayston, R., Wu, Y. T., and Prince, M. (2019). A review of the 10/66 dementia research group. *Social Psychiatry and Psychiatric Epidemiology*. Vol.54(1), p1-10.
- Prince, M. (1997). The need for research on dementia in developing countries. *Tropical Medicine and International Health*. Vol.2(10), p993-1000.
- Prince, M. (2000). Dementia in developing countries: A consensus statement from the 10/66 Dementia Research Group. *International Journal of Geriatric Psychiatry*, 1, 15(1), pp. 14-20.
- Prince, M., Graham, N., Brodaty, H., Rimmer, E., Varghese, M., Chiu, H., Acosta, D., Scazufca, M. (2004). Alzheimer Disease International's 10/66 Dementia Research Group—One model for action research in developing countries. *International Journal of Geriatric Psychiatry*. Vol.19(2), p178-181.
- Prince, M., Acosta, D., Albanese, E., Arizaga, R., Ferri, C.P., Guerra, M., Huang, Y., Jacob, K., Jimenez-Velazquez, I.Z., Rodriguez, J.L., Salas, A., Sosa, A.L., Sousa, R., Uwakwe, R., van der Poel, R., Williams, J., Wortmann, M. (2008). Ageing and dementia in low and middle income countries—Using research to engage with public and policy makers. *International Review of Psychiatry*. Vol.20(4), p332–343.
- Prince, M., Acosta, D., Ferri, C.P., Guerra, M., Huang, Y., Rodriguez, J.J.L., Salas, A., Sosa, A.L., Williams, J.D., Dewey, M.E., Acosta, I., Jotheeswaran, A.T., Liu, Z. (2012). Dementia incidence and mortality in middle-income countries, and associations with indicators of cognitive reserve: a 10/66 Dementia Research Group population-based cohort study. *The Lancet*. Vol.380(9836), p50–58.
- Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W., Ferri, C. (2013). The global prevalence of dementia: A systematic review and metaanalysis. *Alzheimer's & Dementia*. Vol.9, p63-7,e2.
- Prince, M., Wimo, A., Guerchet, M., Ali, G., Wu, Y., Prina, M. (2015). *World Alzheimer Report: The Global Impact of Dementia*. Alzheimer's Disease International.
- Prince, M.J., Acosta, D., Castro-Costa, E., Jackson, J., Shaji, K.S. (2009). Packages of Care for Dementia in Low- and Middle-Income Countries. *PLoS Medicine*. Vol.6(11), p.e1000176.
- Provan, K.G. and Milward, H.B. (1995). A Preliminary Theory of Interorganisational Network Effectiveness: A Comparative Study of Four Community Mental Health Systems. *Administrative Science Quarterly*. Vol.40(1), p1-33.

- Provan, K.G. and Milward, H.B., (2001). Do Networks Really Work? - A Framework for Evaluating Public-Sector Organizational Networks. *Public Administration Review*. Vol.61(4), p414-423.
- Provan, K. G., Fish, A., Sydow, J., (2007). Interorganisational Networks at the Network Level: A Review of the Empirical Literature on Whole Networks. *Journal of Management*. Vol.33(3), p479-516.
- Provan, K. and Sebastian, J. (1998). Networks within networks: Service link overlap, organizational cliques, and network effectiveness. *The Academy of Management Journal*. Vol.41(4), p453-463.
- Raco, M., Burdett, T., and Heaslip, V. (2019). *Exploring an integrated palliative care model for older people: an integrative review*. Emerald Group Publishing Ltd.
- Raeymaeckers, P. (2013). From a Bird's Eye View? A Comparative Analysis of Governance and Network Integration among Human Service Organizations. *Journal of Social Service Research*. Vol.39(3), p416-431.
- Randolph, J. (2009). A Guide to Writing the Dissertation Literature Review. *Practical Assessment, Research, and Evaluation*. Vol.14, p1-13.
- Reuben, D., Evertson, L., Wenger, N., Serrano, K., Chodosh, J., Ercoli, L., Tan, Z. (2013). The University of California at Los Angeles Alzheimer's and Dementia Care program for comprehensive, coordinated, patient-centred care: Preliminary data. *Journal of the American Geriatrics Society*. Vol.61(12) p2214-2218.
- Roberts, I. (2003) Sociology and industrial relations. In: P. Ackers and A. Wilkinson, eds. *Understanding work and employment: industrial relations in transition*. Oxford: Oxford University Press, p31-42.
- Robins, G. (2015). *Doing Social Network Research*. SAGE Publications.
- Rokstad, M., Ugarelli, R., Sægrov, S. (2016). Improving data collection strategies and infrastructure asset management tool utilisation through cost benefit considerations. *Urban Water Journal*. Vol.13(7) p710-726.
- Rosenheck, R., Morrissey, J., Lam, J., Calloway, M., Johnsen, M., Goldman, H., Randolph, F., Blasinsky, M., Fontana, A., Calsyn, R., Teague, G. (1998). Service system integration, access to services, and housing outcomes in a program for homeless persons with severe mental illness. *American Journal of Public Health*. Vol.88(11), p1610–1615.
- Rosow, K., Holzapfel, A., Karlawish, J., Baumgart, M., Bain, L., Khachaturian, A. (2011). Countrywide strategic plans on Alzheimer's disease: Developing the framework for the international battle against Alzheimer's disease. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*. Vol.7(6), p615-621.
- Rossor, M. and Knapp, M., (2015). Can we model a cognitive footprint of interventions and policies to help to meet the global challenge of dementia? *The Lancet*. Vol.386, p1008-1010.

- Rubio, X., and Ugarte, V. (2014). Normatividad y visión societal en políticas públicas participativas de salud en Centroamérica. *Revista Katalysis*. Vol.17(2), p242-251.
- Russ, T., Batty, G., Hearnshaw, G., Fenton, C., Starr, J. (2012). Geographical variation in dementia: Systematic review with meta-analysis. *International Journal of Epidemiology*. Vol.4, p1012–1032.
- Sabat, S.R. and Harré, R., 1992. The Construction and Deconstruction of Self in Alzheimer's Disease. *Ageing and Society*. Vol.12(4), p443.
- Sabat, S.R., (2005). Capacity for decision-making in Alzheimer's disease: Selfhood, positioning and semiotic people. *Australian and New Zealand Journal of Psychiatry*. Vol.39(11–12), p1030–1035.
- Sacks, O. (2015) *On the move: A life*. London. Macmillan Publishers Limited.
- Sáenz, M.R., Acosta, M., Muiser, J., Bermúdez, J.L. (2011). Sistema de Salud Costa Rica. *Salud Publica de Mexico*. Vol.53(supl 2), p156-167.
- Saraceno, B., Terzian, E., Barquero, F., Tognoni, G. (1995). Mental health care in the primary health care setting: a collaborative study in six countries of Central America. *Health Policy Plan*. Vol.10(2), p133–143.
- Sartori, G. 1984. *Social science concepts: a systematic analysis*. Beverly Hills. Sage Publications.
- Sartori, G. 1994. *Comparative constitutional engineering: an inquiry into structures, incentives and outcomes*. Houndmills, Basingstoke. MacMillan.
- Scheper-Hughes, N. and Lock, M. (1987). The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology. *Medical Anthropology Quarterly*. Vol.1(1) p6-41.
- Schubert, C., Boustani, M., Callahan, C., Perkins, A., Carney, C., Fox, C., Hendrie, H. (2006). Comorbidity Profile of Dementia Patients in Primary Care: Are They Sicker? *Journal of the American Geriatrics Society*. Vol.54(1), p104-109.
- Schultz-Jones, B. and Macpherson, J.R. (2006). *Social network analysis studies in the public and private sectors: A cross-professional comparison*. Proceedings of the American Society for Information Science and Technology. Vol.42(1). pNone.
- Scott, D. (2007). Resolving the quantitative-qualitative dilemma: a critical realist approach. *International Journal of Research & Method in Education*. Vol.30(1), p3-17.
- Scott, J. and Carrington, P. (2011). *The SAGE Handbook of Social Network Analysis*. SAGE Publications.
- Segreteria de la Integración Social Centroamericana. (2016). *Plan Estratégico Institucional 2016-2020*. SISCA, Panama City. p1-57.
- Shakespeare, T. and Watson, N. (1997). Defending the Social Model. *Disability and Society*. Vol.12(2), p293-300.

- Shaw, S., Rosen, R., Rumbold, B., (2011). *What is integrated care? Research report*. Nuffield Trust. p1-22.
- Sistema de la Integración Centroamericana. (2019). [Www.sica.int](http://www.sica.int) [Accessed 23-1-19]
- Skidmore, T., Smith, P., Green, J. (2010). *Modern Latin America*. Oxford. 7th edition. Oxford University Press.
- Sonnenberg-Klein, J., Abler, Randal, T., Coyle, E. J., Ai, H. H., (2017). Multidisciplinary Vertically Integrated Teams: Social Network Analysis of Peer Evaluations for Vertically Integrated Projects (VIP) Program Teams. *American Society for Engineering Education*. Paper ID #19072.
- Stokes, G. (2015). To take a lead in dealing with dementia, Latin American countries must do the opposite of what others have done for years. *Financial Times*. p1–2.
- Strandberg-Larsen, M. and Krasnik, A. (2009). Measurement of integrated healthcare delivery: a systematic review of methods and future research directions. *International Journal of Integrated Care*. Vol.9(4 February), p1-10.
- Strandberg-Larsen, M. (2011). Measuring integrated care. *Danish Medical Bulletin*. Vol.58(2), p.B4245.
- Sulmasy, D. (2002). A biopsychosocial-spiritual model for the care of patients at the end of life. *The Gerontologist*. Vol: 42 Spec No (Iii) pp: 24-33
- Sun, F., Chima, E., Wharton, T., Iyengar, V. (2020). National policy actions on dementia in the Americas and Asia-Pacific: Consensus and challenges. *Revista Panamericana de Salud Pública*. Vol.44, p1-6.
- Suter, E., Oelke, N. D., Adair, C. E. & Armitage, G. D. (2009). Ten Key Principles for Successful Health Systems Integration. *Healthc Q*. Vol.13(Spec No), p16–23.
- Swaffer, K. and Low, L. (2016). *Diagnosed with Alzheimers or another dementia*. New Holland Publishers.
- Swain, J. and French, S. (2010). Towards an Affirmation Model of Disability. *Disability and Society*. Vol.15(4), p569-582.
- Taft, L., Fazio, S., Seman, D., Stansell, J. (1997). A psychosocial model of dementia care: theoretical and empirical support. *Archives of Psychiatric Nursing*. Vol.11(1), p13-20.
- Thomas, C. (2004). How is disability understood? An examination of sociological approaches. *Disability & Society*. Vol.19(6), p569-583.
- Tichy, N. M., Tushman, M. L., Fombrun, C. (1979). Social Network Analysis for Organizations. *The Academy of Management Review*. Vol.4(4), p507-519.
- Tjale, A. and Bruce, J. (2007). A concept analysis of holistic nursing care in paediatric nursing. *Curations*. Vol.30(4), p45-52.



Travers, J. and Milgram, S. (1969). An Experimental Study of the Small World Problem. *American Sociological Association*. Vol.32(4), p425-443.

U.S. National Institute on Aging, (2017). *Risk Factors for Dementia*.  
<https://www.nia.nih.gov/alzheimers/publication/dementias/risk-factors-dementia>  
[Accessed 16-7-19]

United Nations, (1983). *Vienna International Plan of Action on Aging*. pp. 1-50.  
<https://digitallibrary.un.org/record/43681?ln=en> [Accessed 24-8-19]

United Nations, (2002). *Madrid political declaration and international plan of action on ageing*. Madrid. <https://www.un.org/development/desa/ageing/madrid-plan-of-action-and-its-implementation.html> [Accessed 24-8-19]

United Nations. 1991. *Principles for Older Persons. General Assembly Resolution*. Number: 46/91.  
<https://www.ohchr.org/en/professionalinterest/pages/olderpersons.aspx#:~:text=Adopted%20by%20General%20Assembly%20resolution%2046%2F91%20of%2016%20December%201991&text=1.,2.> [Accessed 24-8-19]

United Nations. 1992. *Proclamation of Ageing. General Assembly Resolution*. 47/5. <https://www.un.org/development/desa/ageing/resources/international-year-of-older-persons-1999/resolution-475.html> [Accessed 24-8-19]

United Nations. (2004). *Kyoto Declaration: Minimum actions required for the care of people with dementia*. Kyoto.

United Nations. (2012). *Political Declaration of the High-level Meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases*. General Assembly. 66/2. <https://digitallibrary.un.org/record/710899?ln=en>  
[Accessed 25-8-19]

United Nations. (2016). *Convention on the Rights of Persons with Disabilities*. Available: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html> [Accessed 25-8-19]

Upvall, M. and Hashwani, S. (2001). Negotiating the informed-consent process in developing countries: A comparison of Swaziland and Pakistan. *International Nursing Review*. Vol.48(3), p188-192.

Valente, T.W., Palinkas, L.A, Czaja S, Chu K-H, Brown, CH. (2015) Social Network Analysis for Program Implementation. *PLoS ONE*. 10(6), e0131712, p1-18.

Valentijn, P.P., Vrijhoef, H.J.M., Ruwaard, D., Boesveld, I., Arends, R.Y., Bruijnzeels, M.A. (2015). Towards an international taxonomy of integrated primary care: a Delphi consensus approach. *BMC Family Practice*. Vol.16(1), p1-15.  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4446832/> [Accessed 27-10-19].

- Valentijn, P.P., Angus, L., Boesveld, I., Nurjono, M., Ruwaard, D., Vrijhoef, H. (2017). Validating the Rainbow Model of Integrated Care Measurement Tool: results from three pilot studies in The Netherlands, Singapore and Australia. *International Journal of Integrated Care*. Vol.17(3), p.91.
- Van Raak, A. and Paulus, A. (2001). A sociological systems theory of interorganisational network development in health and social care. *Systems Research and Behavioral Science*. Vol.18(3), p207-224.
- Vargas, I., Vázquez, M., Mogollón-Pérez, A., Unger, J.P. (2010). Barriers of access to care in a managed competition model: lessons from Colombia. *BMC Health Services Research*. Vol.10(297), p1-12.
- Vaswani, T.G. (2001). Family Care of the Elderly: Abuse, Neglect and Abandonment. *The Indian Journal of Social Work*. Vol.62(3), p492-505.
- Vázquez, M., Vargas, I., Unger, J.-P., Mogollón, A., Ferreira Da Silva, M., De Paepe, P. (2009). Integrated health care networks in Latin America: toward a conceptual framework for analysis. *Rev Panam Salud Publica/Pan Am J Public Health*. Vol.26(4), p360-367.
- Volpe, U., Amin, H., Ayinde, O.O., et al. (2020). Pathways to care for people with dementia: An international multicentre study. *International Journal Geriatric Psychiatry*. Vol.35, p163– 173.
- Waite, L. (2000). The Family as a Social Organization: Key Ideas for the Twenty-First Century. *Sociology*. Vol.29(3) p463-469.
- Walker, R. and Paddick, S.M. (2019). Dementia prevention in low-income and middle-income countries: a cautious step forward. *The Lancet Global Health*. Vol.7(5), pe538-e539.
- Walker, T. (2017). Approaches to Critical Realism: Bhaskar and Lonergan. *Journal of Critical Realism*. Vol.16(2), p111-127.
- Wang, X., Birch, S., Ma, H., Zhu, W., Meng, Q. (2016). The Structure and Effectiveness of Health Systems: Exploring the Impact of System Integration in Rural China. *International Journal of Integrated Care*. Vol.16(3), pNone.
- Whitehouse, P.J. and George, D. (2008) *The Myth of Alzheimer's*. New York. St. Martin's Press.
- Williams, L. (2002). Language. In: Davies, C. *The Companion to Hispanic Studies*. London. Oxford University Press. p13-31.
- Williamson, T., (2015). Dementia, rights and the social model of disability. *The Journal of Dementia Care*. Vol.23(5), p12-13.
- Wisconsin Bureau of Aging & Long Term Care. (2003). *Definition of Dementia*. Department of Health and Family Services. Vol.4/2403 rev., p21-22.

- World Health Organization. (2014). Country Cooperation Brief: Guatemala, El Salvador, Honduras, Costa Rica, Panama. <https://www.who.int/country-cooperation/what-who-does/strategies-and-briefs/en/> [Accessed 16-2-20]
- World Health Organization. (2013). *Mental Health Action Plan 2013-2020*. WHO Library Cataloguing-in-Publication Data Library Cataloguing-in-Publication Data, pp. 1-44. [https://www.who.int/mental\\_health/publications/action\\_plan/en/](https://www.who.int/mental_health/publications/action_plan/en/) [Accessed 19-2-20]
- World Health Organization, Alzheimer's Disease International. (2012). *Dementia a public health priority*. United Kingdom. p1-112. [Accessed 19-2-20] [https://www.who.int/mental\\_health/publications/dementia\\_report\\_2012/en/](https://www.who.int/mental_health/publications/dementia_report_2012/en/)
- World Health Organization. (2000). *The World Health Report: Health Systems Improving Performance*. Geneva. p1-206. <https://www.who.int/whr/2000/en/> [Accessed 19-2-20]
- World Health Organization. (2000). *Towards an international consensus on policy for long-term care of the ageing*. Milbank Memorial Fund. p1-17. [https://www.who.int/ageing/publications/long\\_term\\_care/en/](https://www.who.int/ageing/publications/long_term_care/en/) [Accessed 24-3-20]
- World Health Organization. (2010). *Strengthening health systems : What works?* Alliance for Health Policy and Systems Research. Annual Report 2009. Geneva. p1-54.
- World Health Organization. (2016). *Framework on integrated, people-centred health services*. Report by the Secretariat. p1-12. [Accessed 25-3-20] <https://www.who.int/servicedeliverysafety/areas/people-centred-care/en/>
- World Health Organization. (2017). *Global action plan on the public health response to dementia 2017–2025*. Geneva. [Accessed 25-3-20] [https://www.who.int/mental\\_health/neurology/dementia/action\\_plan\\_2017\\_2025/en](https://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en)
- World Health Organization. (2018). *Towards a dementia plan: a WHO guide*. Geneva. p1-78. [Accessed 25-3-20] [https://www.who.int/mental\\_health/neurology/dementia/policy\\_guidance/en/](https://www.who.int/mental_health/neurology/dementia/policy_guidance/en/)
- World Health Organization. (2020). Available: <https://www.who.int/> [Accessed 30-3-20]
- World Trade Press. (2010). *Belize Society & Culture Complete Report: An All-Inclusive Profile Combining All of Our Society and Culture Reports*. World Trade Press. ProQuest Ebook Central. [Accessed 20-10-19] <https://ebookcentral.proquest.com/lib/stir/detail.action?docID=535628>
- World Trade Press. (2010). *Costa Rica Society & Culture Complete Report: An All-Inclusive Profile Combining All of Our Society and Culture Reports*. World Trade Press. ProQuest Ebook Central. [Accessed 20-10-19] <https://ebookcentral.proquest.com/lib/stir/detail.action?docID=535738>

World Trade Press. (2010). *El Salvador Society & Culture Complete Report: An All-Inclusive Profile Combining All of Our Society and Culture Reports*. World Trade Press. ProQuest Ebook Central. [Accessed 20-10-19]  
<https://ebookcentral.proquest.com/lib/stir/detail.action?docID=535793>

World Trade Press. (2010). *Guatemala Society & Culture Complete Report: An All-Inclusive Profile Combining All of Our Society and Culture Reports*. World Trade Press. ProQuest Ebook Central. [Accessed 20-10-19]  
<https://ebookcentral.proquest.com/lib/stir/detail.action?docID=535873>

World Trade Press. (2010). *Honduras Society & Culture Complete Report: An All-Inclusive Profile Combining All of Our Society and Culture Reports*. World Trade Press. ProQuest Ebook Central. [Accessed 20-10-19]  
<https://ebookcentral.proquest.com/lib/stir/detail.action?docID=535898>

World Trade Press. (2010). *Nicaragua Society & Culture Complete Report: An All-Inclusive Profile Combining All of Our Society and Culture Reports*. World Trade Press. ProQuest Ebook Central. [Accessed 20-10-19]  
<https://ebookcentral.proquest.com/lib/stir/detail.action?docID=536133>

World Trade Press. (2010). *Panama Society & Culture Complete Report: An All-Inclusive Profile Combining All of Our Society and Culture Reports*. World Trade Press. ProQuest Ebook Central. [Accessed 20-10-19]  
<https://ebookcentral.proquest.com/lib/stir/detail.action?docID=536167>

Wortman, M. (2012). Dementia: a global health priority - highlights from an ADI and World Health Organization report. *Alzheimer's Research & Therapy*. Vol.Sep 21;4(5), p1-40.

Wu, Y.T., Matthews, F.E., Brayne, C. (2014). Dementia: time trends and policy responses. *Maturitas*, Vol.79(2), p191-195.

# Appendices

## Appendix A: Information sheet for families

### Information Sheet for Families

Researcher Bio:

*Name:* Nereide Alhena Curreri

*Nationality:* Italian

PhD student in Dementia Studies

University of Stirling, Scotland UK

*Email:* [n.a.curreri1@stir.ac.uk](mailto:n.a.curreri1@stir.ac.uk)

*Tel.* (local mobile number)

Photo

### **Exploring Services for People with Dementia**

I would like to invite you to take part in my project. Before you decide, I would like to explain why I am doing this project and what your involvement would be. I will read this information sheet to you and answer any questions you may have.

### **What is this study about?**

This research study explores the dementia services in Central American countries. Specifically, I am interested in which organizations provide services and support to people with dementia and their families, and how these organizations are connected to each other. These organizations form a network of service providers, and I aim to understand how this network is structured and how it functions.

### **What is your role?**

- You have been asked to participate in this project because your family is connected to an organization that offers services and support to families with dementia. I would like to collect your views about the organizations that have provided your family with support/services.
- Your participation would involve 2 interviews with me. Interviews will be held in your home, they will take about 1 hour each on 2 different days. All family members are invited to join. I will take notes during the interviews.
- Participation is voluntary, you are not obliged to take part or to answer any question you do not wish to, and you can stop or withdraw at any time.

### **How will the information be used?**

The information you provide will become part of my doctoral thesis. Beyond that, findings may be used for academic publications and conference presentations. I hope that this research will also assist in building strong dementia service networks across the world to support people with dementia and their families.

### **Confidentiality/Anonymity:**

When you take part in this research your identity is kept confidential.

The identities of all participants in the interviews will be kept confidential. Each family will be provided a code name.

Any information provided to me and written in my notes will be stored securely and be password protected. The only people other than myself with access to the data will be my two university doctoral supervisors.

**More information:**

- *If you would like more information about this project or have any concerns with me or my practice please contact:*  
Dr. Louise McCabe  
Tel.  
Email: [l.f.m.mccabe@stir.ac.uk](mailto:l.f.m.mccabe@stir.ac.uk)
- *If you would like support or information about dementia please contact:*  
Alzheimer's Association  
Local contact details per country

## Appendix B: Information sheet for organizations

### Information Sheet for Organizations

#### Researcher Bio:

*Name:* Nereide Alhena Curreri

*Nationality:* Italian

PhD student in Dementia Studies  
University of Stirling, Scotland UK

*Email:* [n.a.curreri1@stir.ac.uk](mailto:n.a.curreri1@stir.ac.uk)

*Tel.* (local mobile number)

Photo

#### **Exploring Services for People with Dementia**

I would like to invite you to take part in my project. Before you decide, I would like to explain why I am doing this project and what your involvement would be.

#### **What is this study about?**

This research study explores the dementia service systems in Central American countries. Specifically, I am interested in which organizations provide services to people with dementia and their families, and how these organizations are connected to each other. These organizations form a network of service providers, and I aim to understand how this network is structured and how it functions from the perspective of the organizations within it and the families it provides services to.

#### **What is your role?**

- You have been asked to participate in this project because the organization you represent provides services or support to families with dementia.
- Your participation would involve 1 interview with me. The interview will be held in your organization's offices, and will take about 1 hour. I will take notes during the interview.
- Participation is voluntary, you are not obliged to take part or to answer any question you do not wish to, and you can stop or withdraw at any time.

#### **How will the information be used?**

The information you provide will become part of my doctoral thesis. Beyond that, findings may be used for academic publications and conference presentations. I hope that this research will also assist in building strong dementia service networks across the world to support people with dementia and their families.

#### **Confidentiality/Anonymity:**

When you take part in this research your identity is kept confidential. The identities of all participants in the interviews will be kept confidential. Each person will be provided a code. The name of your organization will not be anonymized.

Any information provided to me and written in my notes will be stored securely and be password protected. The only people other than myself with access to the data will be my two university doctoral supervisors.

**More information:**

- *If you would like more information about this project or have any concerns with me or my practice please contact:*  
Dr. Louise McCabe  
Tel.  
Email: [l.f.m.mccabe@stir.ac.uk](mailto:l.f.m.mccabe@stir.ac.uk)
- *If you would like support or information about dementia please contact:*  
Alzheimer's Association  
Local contact details per country.



## Appendix C: Interview guide for families

### Family Interview Guide

#### I. BACKGROUND

1. How are you all feeling? How are you managing? (Gain some context on dementia experience.)
2. Age of PwD?
3. Gender?
4. When did symptoms begin?
5. First contacted who about symptoms?
6. How did you know who to contact first?

#### II. FAMILY JOURNEY\*

*Step 1: Families will be asked to make a list of what services are (were) provided to them and the names of organizations providing.*

1. Which organizations are (were) you in contact with? *[Make a list]*
2. Which type(s) of tie do (did) you have with each organization?
  - a. social relation
    - i. How are you related?

- b. interaction - speaking, helping

- i. How does (did) the organization help you or what do (did) you speak about?

- c. Flow - exchange of info, resources, influence

- i. What does (did) the organization exchange with you?

3. How frequently do (did) you interact with this organization?

0 times per week	1-3 times per week	4-6 times per week	7-10 times per week
---------------------	-----------------------	-----------------------	------------------------

4. How important is (was) your tie with this organization?

0	1	2	3	4	5	6	7	8	9	10
Not at all										Very

5. How strong is (was) your tie with this organization? (can rely on)

0	1	2	3	4	5	6	7	8	9	10
Not at all										Very

6. How influential is (was) your tie with this organization? (impacts/affects)

0	1	2	3	4	5	6	7	8	9	10
Not at all										Very

\*this section repeated for each organization with which the families interact(ed)

**III. OTHER ORGANIZATIONS**

1. Which organizations interact with each other? *[note on list]*
2. Which type(s) of ties do the organizations have with each other?

a. social relation

i. How are they related?

--

b. interaction - speaking, helping

i. How do you help each other or what do you speak about?

--

c. Flow - exchange of info, resources, influence

i. What do they exchange?

--

3. How important is the tie between these organizations?

0	1	2	3	4	5	6	7	8	9	10
Not at all										Very

4. How strong is the tie between these organizations?

0	1	2	3	4	5	6	7	8	9	10
Not at all										Very

5. How influential is the tie between these organizations?

0	1	2	3	4	5	6	7	8	9	10
Not at all										Very

6. Which organizations that you've listed do you think communicate to each other about your family's needs?  
*[note on list]*

**IV. CONTEXT**

- A. What older adult and/or dementia policies are you aware of?
- B. What care arrangements are available for people with dementia?

## Appendix D: Interview guide for organizations

### Organization (Service Provider) Interview Guide

#### **I. DEMOGRAPHICS**

1. Organization Represented:
2. Service(s) offered/provided:
3. Representative's role:
4. Target consumer:
5. Year founded:
6. Tot. Number of employees:
7. Tot. Number of clients:

#### **II. OWN ORGANIZATION\***

*Step 1: Representative will be given a list of organizations to edit (from reputational/snowball sampling)*

1. Which organizations does your organization interact (communicate/work) with? *[check off on list]*
  - a. Any not on the list that that you interact (communicate/work) with? *[add on list]*
  
2. Which type(s) of tie does your organization have with each organization?
  - a. social relation
    - i. How are they related?
  - b. interaction - speaking, helping
    - i. How do you help each other or what do you speak about?
  - c. Flow - exchange of info, resources, influence
    - i. What do you exchange?
  
3. On a scale of 1 to 10, how important is the tie with this organization?  
0 1 2 3 4 5 6 7 8 9 10  
Not at all Very
  
4. On a scale of 1 to 10 how strong is the tie with this organization?  
0 1 2 3 4 5 6 7 8 9 10  
Not at all Very
  
5. How influential is the tie with this organization?  
0 1 2 3 4 5 6 7 8 9 10  
Not at all Very

\*this section repeated for each organization with which interaction occurs

**III. OTHER ORGANIZATIONS**

1. Which organizations interact (communicate/work) with each other? *[note on list]*

2. Which type(s) of ties do the organizations have with each other?

a. social relation

i. How are they related?

b. interaction - speaking, helping

i. How do they help each other or what do they speak about?

c. Flow - exchange of info, resources, influence

i. What do they exchange?

3. How important is the tie between these organizations?

0 1 2 3 4 5 6 7 8 9 10  
Not at all Very

4. How strong is the tie between these organizations?

0 1 2 3 4 5 6 7 8 9 10  
Not at all Very

5. How influential is the tie between these organizations?

0 1 2 3 4 5 6 7 8 9 10  
Not at all Very

**IV. CONTEXT**

A. What older adult and/or dementia policies does your organization adhere to

B. What care arrangements are available for people with dementia?

## Appendix E: Verbal Consent protocol

### Verbal Consent Protocol

#### **Exploring Services for People with Dementia**

Thank you for agreeing to be interviewed.

Ethical procedures for academic research undertaken from UK institutions require that interviewees agree to be interviewed and understand how the information collected will be used.

- Your participation is voluntary. You are free to stop or withdraw at any time during the interview. You may ask questions at any time.
- I, the researcher, will take notes during the interview. I may use some of the interview content or direct quotations from the interview in my final thesis, in academic publications or other outlets.
- Any content from the interview will be anonymized so that you cannot be identified.

By consenting to participate in the interview:

1	Do you confirm that you were read the information sheet for the "Exploring Services for People with Dementia" project?	
2	Do you understand that your participation is voluntary and that you are free to stop or withdraw at any time?	
3	Do you agree to take part in this project?	
4	Do you understand and agree that notes from your interview can be used and only anonymously?	
5	Do you agree that you do not expect to receive any benefit or payment for your participation?	

## Appendix F: University Ethics Approval Letter

Alhena Curreri  
Social Sciences  
University of Stirling  
FK9 4LA

[n.a.curreri1@stir.ac.uk](mailto:n.a.curreri1@stir.ac.uk)

7<sup>th</sup> November 2017

Dear Alhena

**Re: Ethics Application: A Social Network Analysis of Dementia Policies and Care Arrangements in Central America (GUEP276)**

Thank you for your submission of the above to the General University Ethics Panel.

I am pleased to confirm that GUEP has approved your application, and you can now proceed with your research.


Please ensure that your research complies with Stirling University policy on storage of research data

<http://www.stir.ac.uk/is/researchers/data/afteryourresearch/>

Please note that should any of your proposal change, a further submission (amendment) to GUEP will be necessary. If your project extends more than 12 months please note you will be subject to further review after these 12 months.

Please be aware that research approved by GUEP may be audited to ensure the research has proceeded in the manner approved. The selection of projects to audit will be done at random.

If you have any further queries, please do not hesitate to contact the Committee by email to [guep@stir.ac.uk](mailto:guep@stir.ac.uk).

Yours sincerely,  
Pp 

On behalf of GUEP  
Professor Helen Cheyne  
**Deputy Chair of GUEP**

