## AT THE INTERPLAY OF CARE AND MIGRATION

EXAMINING THE POTENTIAL OF COMMUNITY HEALTH WORKERS AND LIVE-IN MIGRANT CARE WORKERS TO ANSWER OLDER ADULTS' UNMET CARE NEEDS

Sylvia Hoens





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## CHAPTER 1. INTRODUCTION

#### CHAPTER 1. INTRODUCTION

This chapter presents a general introduction to the dissertation. Section 1 gives an overview of the provision of care to older people, including demographic trends and the institutional, political and gender context of care provision. Section 2 details universal access to care, including the right to access care services, defining access, barriers to care services, exclusion of specific groups and care preferences. Section 3 provides information on alternative approaches to organising care, explaining live-in migrant care workers and community health workers. The chapter ends with the research aim, the dissertation outline and an overview of the different studies.

#### 1 | PROVIDING CARE TO OLDER PEOPLE

#### 1.1 | DEMOGRAPHIC TRENDS

#### 1.1.1 AN AGEING POPULATION

The twenty-first century is characterised by an ageing population, happening in all regions and in countries at different levels of development (United Nations Department of Economic and Social Affairs, 2019). This is the result of rising life expectancy and declining fertility rates, as a result of which the number of older adults is growing faster than any other age group (United Nations Population Fund, 2012). In 2019, there were 703 million people aged 65 and older, representing 1 in 11 people. By 2050 it is estimated that globally 1 in 6 people will be over 65 (United Nations Department of Economic and Social Affairs, 2019).

The transformation towards an ageing population can also be observed in the age structure of the European population. An increasing share of older adults is seen, while the number of working-age people is declining. This is reflected in the population pyramid of 2020, which is more narrow at the bottom (ages 20-49) and wider in the middle (ages 50-85+) compared to 2005 because of the baby boomer generation reaching retirement age (see Figure 1) (Eurostat, 2021).

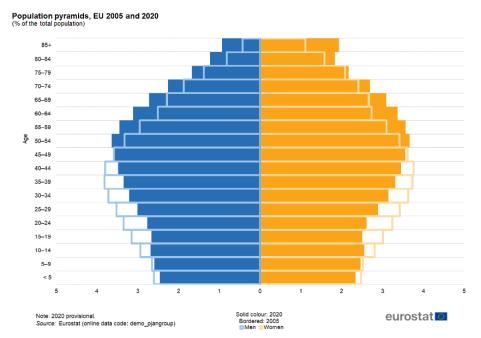
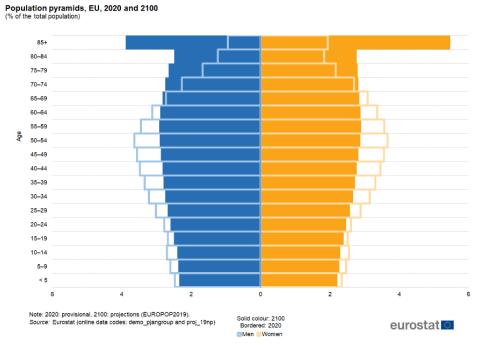
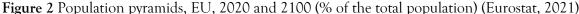


Figure 1 Population pyramids, EU 2005 and 2020 (% of the total population) (Eurostat, 2021)

Eurostat (2021) population projections for 2020 to 2100 show that ageing of the European population is expected to continue, reaching significantly high numbers of older adults in the coming decades. By 2100, the population pyramid is expected to have the shape of a block, with a narrow middle population group (see Figure 2).





Another aspect of population ageing is the growth in people aged 80 and older, a group that is growing faster than other age segments. It is projected that this population will increase from 5.9% in 2020 to 14.6% by 2100 (Eurostat, 2021).

Following global and European trends, Belgium too is facing a growing number of older adults. In 2021, 19.4% of the Belgian population was 65+, and 5.6% of them were 80+ (StatBel, 2021a). The share of individuals 65 and older in Belgium is expected to increase significantly in the coming years, to 23.0% of the total population by 2030, meaning that more than 2 out of 10 individuals in Belgium will be in that age segment (United Nations Department of Economic and Social Affairs, 2019).

The extent of the proportion of older adults differs among Belgian regions. Belgium is a federal state subdivided into three regions: Flanders, Wallonia and the Brussels-Capital Region. Flanders, the northern Dutch-speaking region, is the most populous (6,629,143 inhabitants) and oldest, with 20.8% of its residents aged 65+. In Wallonia, the southern francophone region, the population comprises 3,645,243, with 19.0% aged 65+. Brussels-Capital (total population 1,218,255) is referred to as the 'youngest' region, with 13.1% of residents aged 65+ (StatBel, 2021c).

#### 1.1.2 A HETEROGENEOUS AGEING POPULATION

The older population is not a homogeneous group, which makes one-size-fits-all policies lacking (Van Eenoo et al., 2018). First, just like any other age group the older population is diverse in terms of factors like age, gender, education, ethnicity, income and health. For example, the number of older adults aged 65+ with a migration background in the Brussels-Capital Region increased from 28.0%

in 2011 to 40.9% in 2021 (StatBel, 2021b). Second, the way people age is diverse too. Wide variations are seen in quality of life and health limitations experienced across all ages, which show a differentiation in how people experience ageing today that cannot be tracked by chronological age. The health impact of ageing might already show at an early age for some people, while very late for others (Lowsky et al., 2013).

All persons have different needs and interests that should be taken into account and addressed individually. This shows that a growing ageing society also poses challenges when it comes to the provision of care (United Nations Population Fund, 2012).

#### 1.2 | PROVISION OF CARE SERVICES

1.2.1 THE INSTITUTIONAL ARCHITECTURE OF CARE PROVISION: CARE DIAMOND

In most European countries, a wide range of care services is offered at home, with variations between countries in the availability of care and the way it is provided (van Lier et al., 2021). To capture this variation, and to demonstrate the institutional architecture through which care is provided, Razavi (2007) developed the care diamond (see Figure 3). While the family is often the main actor in providing care to older persons, care is perceived as a public issue and goes beyond the household (Raghuram, 2016). The main actors that provide care are classified in four institutions:

- 1. Family: this includes care provided by partners, children or other close family members. Their care is embedded with emotional and social relations.
- 2. The private market: this includes companies offering care but also looking for profit.
- 3. The state (or public sector): this includes services (e.g. public care centres) as well as cash transfers (e.g. subsidies, informal care budget).
- 4. The not-for-profit sector: this includes voluntary and community care provision, as well as non-profit care organisations.

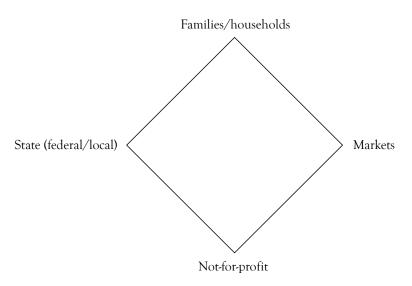


FIGURE 3 The care diamond (Razavi, 2007)

Some types of care services might be difficult to categorise in these four institutions and the boundaries might not always be clear or fixed (i.e. market provision might also interact with state

subsidies and regulations). The role of these main actors of care provision has important implications for who pays, who cares and who is responsible (King-Dejardin, 2019).

Some authors (Radziwinowiczówna et al., 2018) have argued that by defining the four institutions that are providing care, Razavi overlooks the alternative care providers that might be called upon by diverse groups; Razavi has been criticised for her Eurocentric view of care provision. The Eurocentric view of care does not consider the diversity of care practices globally (e.g. care by transnational actors) and the local context and cultures of care in shaping care provision (Radziwinowiczówna et al., 2018; Raghuram, 2016). Local variants of care provision within communities should therefore be considered more, recognising the plurality of care practices (Raghuram (2016). Different actions can contribute to this broader view on care provision, such as including the voices of minorities and recognising different national care models, ideals or cultures of care.

#### 1.2.2 BELGIAN POLICY TRENDS IN CARE SERVICES

Belgian healthcare policy currently places an emphasis on community care. Care used to be provided in institutions, but starting from the 1980s it became de-institutionalised. This entailed that care was provided in the community, by professionals (De Rick et al., 2003). Another shift in community care was seen in 2000, when care was not only provided in the community but also by the community. This means that the focus no longer lies only on formal care organisations, but on greater societal responsibility such as informal care, neighbourly help, self-care, etc. (Vandeurzen, 2013). So currently, policy on community care is understood as the shift in care to enable people with disabilities, chronic illnesses, frailties, behavioural and emotional problems, those living in poverty, and others, to be included in society, to support them where necessary, and to integrate care into society as much as possible (Strategische Adviesraad Welzijn Gezondheid Gezin, 2012). These policy trends are also reflected in the number of Belgian older adults receiving care. Of the 65+ population, 13.6% receive formal long-term care – 8.5% in residential facilities and 5.1% at home (i.e. home nursing). A further 20% receive support from informal carers such as children, family or friends (Federal Public Service Health Food chain safety and Environment, 2019).

Since Belgium has a strong history of residential care provision, this shift towards community care ensured a reorganisation of the entire care chain with a resulting reallocation of investments (Giordano, 2017; Simonazzi, 2009). Several actions have been taken by the Flemish government in the Flemish senior citizens' policy plan 2015-2020 to enable older adults to remain at home for as long as possible (i.e. housing modifications, developing integrated care, promoting care from a network- and client-centred perspective, encouraging informal caregivers) (Flemish Government, 2015).

Belgian older adults can likewise count on a well-developed system of social protection, including cash and in-kind benefits and care allowances. The system of care and support services is multi-layered and governed by federal and regional policies (Pacolet & De Wispelaere, 2018). First, the Federal government is largely responsible for healthcare policy and the financing of healthcare acts, including social security, compulsory health insurance, hospital legislation and pharmaceutical policy. Medical professionals, such as general practitioners, home nurses and home healthcare assistants, are within the authority of the Federal government. Next, the regional level oversees person-related matters, which include care and welfare. Prevention and support services at home (e.g. cleaning services, meals on wheels, family aids) are within the regions' responsibility (European Observatory on Health Systems Policies et al., 2020).

Belgian care provision is traditionally oriented towards providing services rather than cash allowances (Giordano, 2017). Therefore, employment through the service provider organisations' model dominates Belgian home care, which means that a family is not the direct employer as there is a third party acting as intermediator. The care worker is generally employed by a public or private organisation (Farvaque, 2013).

Community care does face several formal and informal care gaps. First, the provision of informal care is decreasing (Colombo et al., 2011; Raghuram, 2016). Family structures are changing, with more single-person households, fewer children per family (Hoff, 2015), and families looking for a better balance between work and parenting. Because women are increasingly engaged in paid employment, it becomes difficult to combine work and domestic responsibilities. As will be explained in the next section, these domestic and care responsibilities are still part of the dominant normative gender role of women (Barry & Jennings, 2021).

Second, home care services are often limited in their ability to provide integrated and personcentred care (Nies, 2015); they may operate in a highly fragmented manner. Even though one of the principles of community care is to fit in with the needs of the person seeking care and therefore requires cooperation across services and sectors, integrated care is not yet a finished realisation (De Donder et al., 2017). In addition, formal care services face budgetary restrictions (Pacolet & De Wispelaere, 2018) and public support for home-based and community-based long-term care services across European member states remains low (European Commission, 2021).

#### 1.2.3 GENDER DISBALANCE IN PROVIDING CARE

Already in 1983, Finch (p. 6) made the critique of feminists on community care clear: "Feminists have increasingly insisted on making explicit the true meaning of 'community care' as it applies to elderly and handicapped people, i.e., for community read family, and for family read women, and have rightly been suspicious of attempts to increase such 'community' provision, seeing them as part of the political agenda of getting women out of the labour market and back into the home, to provide unpaid health and welfare services for members of their own families." This time marked the starting point of studies on the caregiving role of women (Degavre & Nyssens, 2010).

This gender disbalance is nonetheless still reflected in the current numbers, and with four in five (81%) employees in European long-term care being women, the care sector is an overwhelmingly female sector (Eurofound, 2020). More specifically, in Belgium 25% of all women participating in the labour market work in the care sector (e.g. as nurses, care assistants, doctors, social workers, administrative staff, cleaning and maintenance staff) (StatBel, 2020). Outside the labour market, it is also women who take up the biggest chunk of care in the private sphere (European Institute for Gender Equality (EIGE), 2021). Unpaid care is often seen as women's responsibility (King-Dejardin, 2019). In 2020, care activities were shared equally by only one in three European families. In this sense, care responsibilities keep 7.7 million women in Europe out of the labour market (European Institute for Gender Equality (EIGE), 2021).

Throughout history, care has always been provided by women (Fine & Glendinning, 2005; King-Dejardin, 2019). Caring is regarded as consumptive and unproductive, and thus not economically valuable. Despite women's increasing participation in the labour market, the 'male breadwinner' notion defining the dominant normative gender relations remains valid, where men engage in paid work and women take care of the family (Barry & Jennings, 2021; King-Dejardin, 2019). Despite women's time spent on paid/unpaid care, support systems are still missing (Barry & Jennings, 2021).

#### 2 | UNIVERSAL ACCESS TO CARE

#### 2.1 | THE RIGHT TO ACCESS CARE SERVICES

The United Nations Declaration of Human Rights in 1948 affirmed health as a human right for all, regardless of socio-economic status, religion, gender, sexuality, nationality or ethnic origin. It is described as 'health for all' (United Nations, 1948). Universal access to care is also put forward as one of the targets for the UN's Sustainable Development Goals (United Nations, 2022). In this context, the World Health Organization defined access as the absence of sociocultural, organisational, economic, geographical and gender-related barriers (Evans et al., 2013). The United Nations member states underlined this goal by signing the Development Goals, including achieving universal health coverage by 2030. This entails the capacity of health systems to respond to the needs of the population at any care level, without causing financial damage, and ensuring access to quality essential healthcare services (World Health Organization, 2018).

Realising the right of older adults to enjoy the highest attainable health requires governments to generate conditions that allow everyone to be as healthy as possible (Gil-González et al., 2015). These conditions include guaranteeing access to adequate care services (United Nations Population Fund, 2012). The European Pillar of Social Rights endorses this right to access adequate care services by the principle of long-term care: "Everyone has the right to affordable long-term care services of good quality, in particular home-care and community-based services."

#### 2.2 | DEFINING ACCESS

In defining 'access', Levesque et al. (2013, p. 1) based his understanding on conceptualisations of different authors (i.e. Daniels, 1982; Whitehead, 1992): "Within health care, access is always defined as access to a service, a provider or an institution, thus defined as the opportunity or ease with which consumers or communities are able to use appropriate services in proportion to their needs". Levesque et al. (2013, p. 8) further distinguish the different stages of access and perceive access as: "the opportunity to identify healthcare needs, to seek healthcare services, to reach, to obtain or use healthcare services and to actually have the need for services fulfilled." Different conceptualisations of access vary in their description of characteristics of care providers and of the actual process of care (i.e. the way in which access is realised). Most authors recognise that access is influenced by characteristics of both users and providers. Demand for services also includes personal preferences, tastes and information. However, emphasis is also put on care resources that influence the utilisation of services, acting as a mediating factor between the capability to deliver and to consume services (Levesque et al., 2013). To capture these two, Penchansky and Thomas (1981) conceptualise access as the fit between characteristics of care service providers and characteristics and expectations of users. Hence utilisation of services, or realised access, is determined by both the supply and demand for services (Levesque et al., 2013). In this sense, access transcends the mere availability of services. A comprehensive view on access considers structural characteristics of care providers, characteristics of individual users and process factors.

#### 2.3 | BARRIERS TO CARE SERVICES

In assessing the aspects that define access and barriers towards care services, the framework of Penchansky and Thomas (1981), as validated and adapted for the Belgian context by Fret et al. (2019), can be used. Access is "a general concept that summarises a set of more specific dimensions describing the fit between the patient and the healthcare system" (Penchansky & Thomas, 1981, p. 127). Measuring access to care and associated barriers entails five aspects: availability, accessibility, adequacy, affordability and acceptability (Penchansky & Thomas, 1981). Upon re-evaluating and extending the framework to the actual context, Saurman (2016) added a sixth aspect: awareness. This framework was applied multiple times in the wider context of access to services (Unesco Director-General, 2013). Fret et al. (2019) used it to assess access to homecare for older adults in Belgium, after which a seventh aspect was added: ageism. These seven aspects, 'the seven A's', are:

- 1. "Affordability is determined by how the provider's charges relate to the client's ability and willingness to pay for services";
- 2. "Availability measures the extent to which the provider has the requisite resources, such as personnel and technology, to meet the needs of the client";
- 3. "Accessibility refers to geographic accessibility, which is determined by how easily the client can physically reach the provider's location";
- 4. "Adequacy (or accommodation) reflects the extent to which the provider's operation is organised in ways that meet the constraints and preferences of the client.";
- 5. "Acceptability captures the extent to which the client is comfortable with the more immutable characteristics of the provider, and vice versa. These characteristics include the age, sex, social class, and ethnicity of the provider (and of the client), as well as the diagnosis and type of coverage of the client" (Wyszewianski & McLaughlin, 2002, p. 1441).
- 6. "Awareness refers to effective communication and information strategies with relevant users (clinicians, patients, the broader community)" (Saurman, 2016, p. 37).
- Ageism concerns stereotypes towards older adults that limit qualitative elder care (Fret et al., 2019).

The various aspects of access are intertwined, therefore improving one barrier can positively impact another (Fret et al., 2019; Levesque et al., 2013). The various aspects of access are multidimensional and also point to the importance of taking into account individual characteristics of people with care needs (i.e. socio-economic factors, trust), which especially influences acceptability yet is often neglected (Fret et al., 2019).

#### 2.4 | EXCLUSION OF SPECIFIC GROUPS FROM CARE SERVICES

Even though the abovementioned 'health for all' campaign is powerful, certain groups who are potentially vulnerable to different health risks still lack sufficient access to health services. This enforces the already-existing health inequalities. In the European Union, almost one in three households live without adequate professional home care services (European Institute for Gender Equality (EIGE), 2020). Access to adequate services is often not fulfilled for deprived and vulnerable groups who have high health needs These differences between societal groups' access to care stress the importance of taking into account the influence of structural, contextual (i.e. care system and physical, political, economic or social environment) and individual barriers (i.e. behaviour of providers and users) on access to care (Gil-González et al., 2015).

In the case of Belgium, 6.4% of older adults report care shortages (De Witte et al., 2010). However, the Organisation for Economic Co-operation and Development (2016) states that "*while its average level of unmet care needs is low, Belgium shows large inequalities*". In Belgium, 8% of households indicate postponing care for financial reasons. People with a low income postpone or reject medical tests more often, due to financial costs, waiting times or travel distance, compared to those with a high income. The care a person receives is determined by her demographic, social and economic characteristics as well as by the characteristics of the environment (Levesque et al., 2013). In other words, regardless of the theoretical right to care for all, in practice access might be restricted due to financial, organisational, linguistic and cultural barriers (Whitehead, 1992).

In addition, certain groups face extra barriers towards care or experience the barriers more intensely. Households with low incomes, lower educational levels and migrant households experience the greatest difficulty in accessing formal home-based long-term care services (Barry & Jennings, 2021).

When looking more specifically into the group of older people with a migration background, research in the Netherlands shows that they make almost no use of home care services (Suurmond et al., 2016). Researchers do predict that the demand for formal care will increase among this group, as a supplement or replacement for informal care (Fokkema et al., 2016). However, professional home care providers are facing barriers in reaching this population. It remains a challenge for home care providers to offer appropriate services to older people from diverse linguistic, cultural, ethnic and religious backgrounds (Suurmond et al., 2016). Even though it is often argued that cultural barriers cause difficult access, the role of institutionalised inequality – such as the intersection of racism and ageism – in explaining care barriers should also be taken into account (Berdai Chaouni et al., 2021). Barriers are detected at three levels.

First, personal barriers can be detected among older adults with a migration background: language barriers, lack of knowledge of the healthcare system, lack of social networks facilitating access to timely care, cultural factors influencing health-seeking behaviour and insecurities related to intercultural encounters (Ahaddour et al., 2016; Kristiansen et al., 2016; Stewart et al., 2011).

Second, there are barriers at the institutional level (Stewart et al., 2011). This concerns the inadequacy of care organisations in addressing the needs of older adults with a migration background (Berdai Chaouni & De Donder, 2019; Gil-González et al., 2015; Suurmond et al., 2016) – for example one-size-fits-all approaches, which ignore the diverse preferences and needs of individuals based on gender, religion, sexual orientation, disability or cultural heritage (Berdai Chaouni & De Donder, 2019; Suurmond et al., 2016). Additionally, care professionals within these institutions lack cultural competences, as is demonstrated by narrow perceptions of a 'homogeneous problematic group with special needs', insecurity and fear to handle incorrectly, and othering practices (Claeys et al., 2020). These othering practices also include stereotyping and racism among professionals, preventing them from seeing individuals with their individual needs (Berdai Chaouni et al., 2021; Berdai Chaouni & De Donder, 2019). Considering these individual preferences, the barriers encountered by older people with a migration background are not exclusive to them. However, the language and communication barriers they may encounter magnify the barriers (Suurmond et al., 2016).

Third, systemic barriers play a role. These include government policies (Stewart et al., 2011), laws and regulatory restrictions influencing the access to care. They also depend on the type of care model in each country and the right of entitlement of vulnerable groups (Gil-González et al., 2015). This facilitates the presence of structural barriers, leading to inequity in accessing care (Berdai Chaouni & De Donder, 2019).

## 2.5 | PREFERENCES TOWARDS PROVIDING AND RECEIVING CARE: ETHNOMORALITY OF CARE

Radziwinowiczówna et al. (2018) originally conceptualised ethnomorality of care in their research about care for older people in transnational families as a concept to explain the experience of care by caregivers and care receivers. It explores intentions, moral beliefs and care arrangements. In understanding the concept, it is important to acknowledge the interplay between what people think is morally acceptable for care (moral beliefs), what they plan to do in the future (care intentions), and what they actually do to provide care (care arrangements). In addition, ethnomorality of care recognises the contexts that shape the experience of care, which includes national and local contexts, economics, gender, and care and migration regimes.

Hence within this concept three dimensions define the experience of care (see Figure 4): 1) Moral beliefs, expressed by moral assumptions on what is believed to be a proper way to provide care, what is the right thing to do, and what should be done in general, in connection with social norms; 2) Care intentions, referring to the mediation between considering what is morally accepted and what is possible within a given opportunity structure (this includes the perspectives of both providing and receiving care); and 3) Care arrangements, including the actual care actions resulting from the negotiation between various social actors (i.e. older person, network of local and transnational kin, informal carers, institutions and nongovernmental organisations). Radziwinowiczówna et al. (2018) argue that the concept of ethnomorality is not limited to transnational families, which was their study population, but can also be applied to a broader population since it enables us to understand the lived experience of care and presents the interactions and possible contradictions between beliefs, intentions and actions.

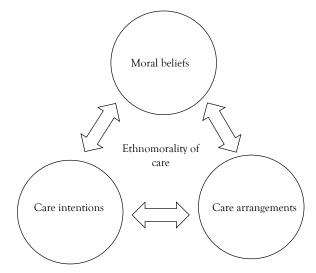


FIGURE 4 Ethnomorality of care (Radziwinowiczówna et al., 2018)

In the interplay between the three dimensions there is a gap where moral beliefs, care intentions and care arrangements do not find each other. This keeps older adults from the care they want to receive, and at the same time keeps care workers and care organisations from the care they want to provide. In order to provide quality care, this gap should be reduced as much as possible. Empowering care workers and care organisations can be a first step towards reducing this gap.

Van Regenmortel (2002, p. 76) defines empowerment as "a process of amplification through which individuals, organisations and communities gain control over their own situations and their environments and do so through gaining control, sharpening critical consciousness and encouraging participation". While most literature has focused on individual empowerment, empowerment is seen as a multilevel concept and can be broadened to organisational and community empowerment (Noordink et al., 2021; Rothman et al., 2019). Organisational empowerment refers to "organizational efforts that generate individual empowerment among members and organizational effectiveness needed for goal achievement" (Peterson & Zimmerman, 2004, p. 130). Community empowerment is understood as "the process of enabling communities to increase control over their lives" (World Health Organization, 2022). The different levels however are interconnected and interdependent. This implies that individuals are constantly influenced by their environments (Noordink et al., 2021), which consist of social, cultural, economic and political determinants (World Health Organization, 2022).

#### 3 | ALTERNATIVE APPROACHES TO ORGANISING CARE

As also demonstrated in section 2 on universal access to care, service providers nowadays often find it complex to adapt their services to the needs of diverse populations (Phillimore et al., 2019). Care workers need to develop knowledge on how to meet people's needs, tailored services should be offered in different languages, and particular groups need extra support to access services (Phillimore, 2011). In addition to state-provided care, people utilise services from many places, using knowledge of various healing systems and transnational networks (Phillimore et al., 2019).

Even though evidence shows that universal services do not offer equal access to services, this has not resulted in adaptation of these services (Phillimore et al., 2019). The general population would benefit from holistic and inclusive strategies to address care needs. This approach could consider the wider role of the state in care provision and the ways in which people themselves act to look for care services that answer their needs (Phillimore et al., 2021), looking also at alternative care services available outside the mainstream care offerings and transcending the Eurocentric view (Radziwinowiczówna et al., 2018). So while formal care provision is under pressure, in recent decades the arising old-age care gaps have been answered by employing migrants in both institutional settings and private households (Da Roit & Weicht, 2013; Weicht, 2021). Two alternative strategies currently in use are healthcare bricolage approaches by hiring live-in migrant care workers employed by private households, and outreach approaches implemented by community health workers employed by organisations. These two cases will be explained below.

## 3.1 | HEALTHCARE BRICOLAGE APPROACHES: THE CASE OF LIVE-IN MIGRANT CARE WORKERS

The concept of healthcare bricolage was developed by Phillimore et al. (2019) in a research project to understand the ways in which care was accessed by residents of superdiverse European

neighbourhoods. It conceptualises the processes and resources employed to access care in demographically diverse areas (Phillimore et al., 2019). These areas are characterised by a population with different origin, cultures, migrant and employment statuses, rights and entitlements, and spatial distributions (Vertovec, 2007). The concept of bricolage recognises that individuals use multiple health resources from multiple places to answer their health concerns (Phillimore et al., 2019). "Bricolage is frequently a response to scarce resources (Halme et al. 2012) and a way of overcoming challenges, turning them into opportunities, through mobilising, mixing, re-assembling and re-using resources to 'make do'" (Phillimore et al., 2019, p. 6). Bricolage can take place in resource-rich or resource-poor environments. Bricolage in resource-rich environments is used as an innovative and creative alternative or addition to mainstream approaches, ensuring better outcomes (Burgers et al., 2014). Healthcare bricolage in this sense is a "creative mobilisation, use and reuse, of wide-ranging resources, including various knowledge resources, and multiple ideas, materials and networks in order to address particular health concerns" (Phillimore et al., 2021, p. 60). On the other hand, areas characterised by superdiverse populations might be resource-poor and need bricolage to overcome barriers to access care (Phillimore, 2011, 2015). Phillimore et al. (2019, p. 6) adds "the co-existence of different belief systems, educational and cultural backgrounds, languages, networks and institutional awareness may widen the range of resources available for mixing, re-making, combining and re-imagining. A combination of local, regional and transnational resources may be harnessed to find creative alternatives or additions to existing approaches to meeting health concerns." So healthcare bricolage entails actions individuals undertake to either augment existing services as an alternative, or go beyond them (Phillimore et al., 2019). The ability to bricolage might depend on the capacity to be mobile, financial resources, the scope of networks, access to navigators, and the proximity of alternative care resources (Phillimore et al., 2021).

In response to the aforementioned informal and formal care gaps, older people are turning to alternative solutions, one of which is to employ live-in migrant care workers (Anderson, 2012). So these older people and their families are employing live-in care workers directly or via care agencies, as an addition to the mainstream services (King-Dejardin, 2019). Live-in migrant care workers are generally defined as: *"informal carers, usually women from third countries who are privately employed by the older person or by their family members to meet the needs for domiciliary support and care"* (Di Santo & Ceruzzi, 2010, p. 4). Live-in migrant carers often provide more affordable long-term care in the older adult's home compared with round-the-clock care offered by national healthcare providers (Lamura et al., 2013; Schwiter, Berndt, et al., 2018).

While in some countries hiring a live-in migrant carer seems an obvious and systematic solution (e.g. Italy (Boccagni, 2018), Germany (Horn et al., 2019), Austria (Schwiter, Strauss, et al., 2018)), in other countries the concept is still in development (e.g. The Netherlands (Da Roit & van Bochove, 2017), United Kingdom (Schwiter, Strauss, et al., 2018)). While this care arrangement is now also emerging in Belgium (Giordano, 2021; Hoens & Smetcoren, 2021), and growing interest and recognition of live-in migrant carers at the European level (i.e. EESC, 2016; EESC, 2018) and at the national Belgian level (i.e. as shown in policy documents (Flemish Parliament, 2014, 2019)) is observed, research in Belgium remains scarce and general, focusing mostly on migrant domestic workers (i.e. Giordano, 2017; Safuta, 2017) and not on live-in migrant care workers.

Depending on geography, cultural preferences, and employment, migration and care policies, live-in migrant care work varies across countries in its exact forms of employment (Ayalon, 2021; Horn et al., 2021; van Hooren, 2020), formalisation, carers' countries of origin and care arrangements (Eurofound, 2020). It is therefore difficult to grasp the exact forms and numbers of this care

arrangement, as it remains largely underreported (Ayalon, 2021; Eurofound, 2020; King-Dejardin, 2019). Little information is available on live-in care, and data collection is challenging because of the often-unregulated and undeclared work, and employers often being single-person households (Eurofound, 2020). Additionally, no occupational definition of a live-in carer is available, and European and member state levels use different categorisations, such as domestic worker or care worker (EESC, 2016). Generally, live-in migrant care arrangements are only recently emerging in countries with more extensive public long-term care services, such as the Netherlands or Austria (Böcker et al., 2020). An overview of the employment of live-in migrant care workers in different countries (i.e. Belgium, Germany, Italy, the Netherlands, Canada and Israel) is given below.

Concrete numbers on the Belgian situation are lacking because of the aforementioned reasons. However, numbers are available on the overall home-based caregivers (i.e. including live-in and liveout workers): in 2013, 14.6% (N=5100) of home-based caregivers in Belgium were foreign-born (OECD, 2015). In this dataset home-based caregivers were defined as "nurses, nursing aides and lessskilled carers who provide help in the home for older and disabled persons including activities of daily living, such as bathing, dressing, and getting in and out of bed" (King-Dejardin, 2019, p. 36). Also, clear regulations for live-in migrant carers are lacking in Belgium. They are working under different care services, as also explained by Giordano (2021, p. 83): "The care providers that do not have any accreditation with public bodies include both non-profit and for-profit organizations and represent a more heterogeneous group. Since these care providers are not subjected to institutional regulations, they respond to different needs and different beneficiaries and offer services that vary enormously in terms of price and type of services. Since the profile of workers is not fixed by law, they usually work under the common label of care/health attendants (garde-malade)." Live-in migrant carers in Belgium often work under this label too. Three types of providers for live-in care can be found in the Brussels-Capital Region: (1) private agencies offering care services by selfemployed workers, (2) online platforms of 'collaborative economy' where private persons offer care services in exchange for non-imposable payment, and (3) private organisations offering live-in care with carers mostly from Eastern European countries (Giordano, 2021).

In Germany, live-in migrant care arrangements are widely used by the older population. It is estimated that between 100,000 and 300,000 older Germans are being cared for by live-in migrant carers, most of them from Eastern and Central European countries (Böcker et al., 2020; EESC, 2020). Schedules have shifting patterns, in which they work some weeks and go back to their country of origin for another few weeks (Eurofound, 2020). More than 250 agencies are active in the sector (Böcker et al., 2020).

Live-in care migrant care arrangements are widely used in Italy too. In 2010, one in four older adults with dementia were cared for by a live-in migrant carer at home (Lamura et al., 2010). Broader numbers show that in 2018, 40% (N=160,000) of regular domestic care workers had a live-in arrangement. The number might even be double if undeclared work was counted. Most live-in carers in Italy are Philippine, although in areas bordering Croatia there is an overrepresentation of Croatian live-in carers (Eurofound, 2020).

This care provision has also been emerging in the Netherlands since 2012, yet remains smallscale. According to a recent estimate, less than 1000 older Dutch adults are cared for by a live-in migrant carer, mainly from Eastern and Central European countries (Böcker et al., 2020) – more specifically from Czechia, Poland, Greece and Portugal (Eurofound, 2020). Recent developments in long-term care in the Netherlands make an increase in live-in migrant care services expectable. However, agencies employing live-in migrant carers have observed a stagnation. In 2018, about 20 agencies were active in the sector (Bruquetas-Callejo & Noordhuizen, 2020).

Live-in migrant care arrangements can also be found in non-European contexts, and some countries have applied strong measures to regulate the sector. Canada, for instance, developed the Canadian Live-in Caregiver Program already in 1992, to allow individuals to migrate temporarily and provide care in Canada. After working for a period, they could become permanent residents (Chowdhury & Gutman, 2012; Salami et al., 2014). Its successor programme still offers the possibility for live-in carers to apply for permanent residence status if they meet certain requirements (Schwiter, Strauss, et al., 2018). Along with Canada, Israel took regulations to protect live-in migrant carers, establishing their minimum living and working conditions. These entail a written contract with the job description, working hours, rest days, salary, etc. About one in four older persons cared for at home have the assistance of a live-in migrant carer (Cohen-Mansfield et al., 2017).

Research by Da Roit and van Bochove (2014) indicates that older adults who hire a live-in migrant care worker often need constant care and assistance with most of their daily tasks. In this case, informal resources are often inadequate to meet such needs. Besides, older adults and family members are not always in favour of residential care services, as demonstrated by research in Italy and the UK (Shutes & Chiatti, 2012; van Grafhorst, 2014). When an older person needs 24-hour care, a live-in migrant care worker is a possible addition to the care already being provided (Shutes & Chiatti, 2012).

Live-in migrant care workers are recruited for different tasks that go beyond medical aspects, also including physical, social, psychological, financial and administrative tasks (van Grafhorst, 2014). Most of the time, they assist with the housekeeping and daily activities such as cooking and getting dressed. They likewise provide companionship to reduce the social isolation of older adults (Lamura et al., 2013), thereby reducing a perceived lack of family support (Østbye et al., 2013).

Several studies have found that older adults with live-in carers experience positive health outcomes (Ayalon, 2011; Østbye et al., 2013; Porat & Iecovich, 2010). These result from the wide availability of live-in carers who provide round-the-clock care (Ayalon, 2009).

#### 3.2 | OUTREACH APPROACHES: THE CASE OF COMMUNITY HEALTH WORKERS

To gain insight into what facilitates access to care, we want to build on the criticism within gerontological research on older migrants and health inequality, stating that the often-used essentialist view on ethnicity (i.e. ethnicity as a fixed characteristic of a homogenous group) oversimplifies the barriers to access (Torres, 2015). It individualizes the 'failure' of minority groups to access care, by first placing the responsibility within the group itself rather than emphasising what care providers can do (Torres, 2019). We therefore want to focus on the role of the organisation to facilitate or generate access to care services.

The role of place is of the utmost importance within outreach programmes. In this sense, services must not only be made physically proximate, but also close in the relational sense (i.e. social distance) (Carlsson & Pijpers, 2020). While acknowledging the diversity of outreach programmes and the difficulties with finding an appropriate definition, Shin et al. (2020, p. 7) define outreach "*as a temporary, mobile project that engages the collaboration of a community to undertake its purposeful health intervention to reach the population at health risk*". Dewson et al. (2006, p. 1) explain that outreach "essentially entails services being taken out from their normative and mainstream institutional settings and being

provided in local community settings. In the welfare-to-work arena, outreach services are used to engage customers, and deliver welfare-to-work services in local settings and environments". Outreach services can get to populations that are not always reached by mainstream services. In this sense they can increase the visibility of services and inform people in their own living environment (Dewson et al., 2006). Professionals will not be waiting behind their desk until patients come to ask for help – instead, they will take the initiative to look for people in their neighbourhood and inform and offer appropriate care services. In this sense, the outreach approach also questions the existence of hard-to-reach populations, stating that it might be rather the care services which are hard to reach. The working procedure of care services comes with certain barriers that make them inaccessible (De Visscher, 2018; Van Doorn et al., 2013). The outreach professional is a familiar face to residents because of their visibility and presence in the neighbourhood. The professional makes personal contact with people and is easily approachable for questions (Omlo, 2017). Once initial contact has been made, it might be easier for older people to access mainstream services (Phillimore et al., 2021).

To improve accessibility of care services through working in the community, research has called to collaborate with a specific type of outreach professionals: community health workers with a migration background (Delgado, 2020). Community health workers "serve as a link between patients and health care providers in order to reduce health care disparities" (Shommu et al., 2016, p. 2). Different terms are used to describe community health workers (health coach, health educator, outreach worker, liaison, health promoter), pointing at various roles and responsibilities (Delgado, 2020; O'Brien et al., 2009), yet their primary goal remains reaching the people most in need of care and the "hard-to-reach groups" (Delgado, 2020). A comprehensive definition is provided by the American Public Health Association (2020): "Community health workers are frontline public health workers who are trusted members of and/or have an unusually close understanding of the community served. This trusting relationship enables community health workers to serve as a liaison/link/intermediary between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery".

Benefits of working with community health workers can be seen at the level of care recipients, by building their trust via home visits (Malcarney et al., 2017), through health-related patient and community empowerment (Delgado, 2020; Malcarney et al., 2017), and by connecting people to broader services (such as transport and housing) as they focus on social determinants of health (Malcarney et al., 2017). On a personal level, community health workers feel a personal responsibility to disseminate knowledge, promote healthy behaviours in their community, and improve health services (Ludwick et al., 2014; Schurer et al., 2020). By improving health services, community health workers feel proud to contribute to the community (Ngilangwa & Mgomella, 2018; Schurer et al., 2020).

Also in Belgium, a growing number of projects recognise the importance of community health workers. During the COVID-19 crisis, for example, in January 2021 Federal Minister of Public Health Franck Vandenbroucke introduced a project to employ 50 community health workers in several cities across Belgium, managed by the health insurance funds. The goals formulated by the government were to:

"- improve access to health care, especially during this [COVID] crisis

- support vulnerable groups in the area of healthcare, so that they do not become more disadvantaged during this crisis

- signal the inequality and structural accessibility problems within the healthcare sector, with extra attention for COVID effects" (FOD Kanselarij van de Eerste Minister, 2021).

Their specific tasks consist of:

- 1. "Identifying barriers in access to care and provide support tailored to the individual with the aim of: recognising the need for care by the person himself, reducing and, if possible, removing those barriers
- 2. Guiding people to care and welfare institutions such as general practitioner, dentist, health insurance fund, ...
- 3. Supporting vulnerable groups in the use of health care by reminding people of appointments, monitor appointments, give confidence and provide trust, listen to the people and valorize their needs
- 4. Strengthen health skills, paying particular attention to the needs related to the COVID crisis.
- 5. Identifying inequalities and structural accessibility problems within primary health care by detecting problems from real life experiences and demands for help" (Intermut, 2021)

#### 4 | RESEARCH AIM

As mentioned above, the heterogeneous older population comes with diverse care needs, so a one-size-fits-all approach does not work (Van Eenoo et al., 2018). Access to care services is not realised for all, as certain needs are not addressed in the formal care offering and several barriers hinder access. However, when facing barriers older people's needs are often pointed to as 'special', requiring interventions to fit into mainstream services and blaming individuals for the barriers they are facing (Phillimore et al., 2019). Additionally, care has previously been defined in a rather Eurocentric way (Radziwinowiczówna et al., 2018; Raghuram, 2016), by identifying the four institutions providing care (family, market, state, not-for-profit sector) (Razavi, 2007). Given the lack in research, we consider the diversity of care provision and have attention for innovative care workers, such as community health workers and live-in migrant care workers. The overall aim of this dissertation is to **explore alternative approaches in organising care for older adults whose care needs are currently not met by formal care services.** Three sub-aims are formulated on different levels, to look beyond older adults' needs and also include care workers and care organisations:

- 1. To explore the potential of alternative care workers in addressing older adults' unmet care needs
- 2. To explore how alternative care workers can be empowered to better address diverse care needs of older adults
- 3. To explore how care organisations can be empowered to better address diverse care needs of older adults

#### 5 | OUTLINE OF THE DISSERTATION

This dissertation is divided into seven chapters. **Chapter 1** presents a general introduction to the dissertation. To frame the rationale behind the dissertation, an overview of the literature is given on providing care to older people, universal access to care and alternative approaches to organising care. This chapter concludes with the research aim and outline of the dissertation.

**Chapter 2** provides an overview of the methodological approach used in the different studies. It includes the research paradigm, a description of the data used in this dissertation and a positionality statement of the researcher.

The study presented in **Chapter 3** identifies the motivations and experiences of older adults and their families who hire a live-in migrant care worker. Data are derived from eight individual interviews with older adults or informal carers, and one focus group (N=6) and five individual interviews with professionals.

**Chapter 4** looks at the other side of live-in care arrangements, by examining the experiences of live-in migrant carers and their decision to migrate. Attention is paid to how they deal with personal and social changes stemming from their work and migration, and how they cope with their working and living conditions. This study applies a narrative approach and presents the 15 interviews with live-in migrant carers as collective vignettes.

Chapter 5 presents a study on a work-training programme for community health workers and applies the Most Significant Change technique. In this two-phase technique individual interviews (N=9) and a focus group (N=7) were used to investigate the most significant change experienced by the community health workers and the enabling and disabling factors in reaching this change.

The study presented in **Chapter 6** investigates how the abovementioned work-training programme for community health workers has contributed to culturally competent home care organisations. Through realist evaluation, individual interviews (N=10) with community health workers and four focus groups (N=25) with stakeholders are used to establish a Context-Mechanisms-Outcomes configuration.

The dissertation ends with a general discussion in **Chapter 7**. The main findings of the different studies are discussed, as well as implications for policy and practice. Methodological reflections are presented and limitations of the dissertation are acknowledged.

Table 1 shows an overview of the studies included in this dissertation. In addition to the overall research aim, each of these studies formulated specific research questions. As Chapters 2 to 5 were originally written as stand-alone articles aimed for publication in international scientific journals, there might be some overlap. By the same token, they can also be read independently.

TABLE 1 Overview of studies included in this dissertation

|   | Research Questions  | Research Method   | Data   | Publication Status  |
|---|---|---|--|---|
| <b>Chapter 3.</b> Hiring live-in migrant<br>care workers: Motivations and<br>experiences of older people and<br>their families  | <ol> <li>What are the motivations of older adults and<br/>their families to hire a live-in migrant care worker?</li> <li>How do older adults and their families<br/>experience the presence and care of a live-in<br/>migrant care worker?</li> </ol>   | Qualitative interviews and focus group  | <ol> <li>Individual interviews with older<br/>persons/their informal carers (N=8);</li> <li>Focus group (N=6) and individual<br/>interviews with professionals (N=5)</li> </ol>  | Published in<br>Journal of<br>Population Ageing               |
| <b>Chapter 4.</b> "I am proud because I<br>support my children and give them a<br>better life": Exploring narratives of<br>live-in migrant care workers<br>through collective vignettes | <ol> <li>How do live-in migrant carers in Belgium explain<br/>their decision to migrate and perform live-in<br/>migrant care work?</li> <li>How do live-in migrant carers experience and<br/>deal with the personal and social changes resulting<br/>from migration and work as live-in carers?</li> <li>How do live-in migrant carers make sense of and<br/>cope with their working and living conditions?</li> </ol>      | Narrative research<br>underpinned with collective<br>vignettes, with serial<br>qualitative interviews | <ol> <li>Individual interviews with live-in<br/>migrant care workers (N=10);</li> <li>Member check + Follow-up<br/>interviews with live-in migrant care<br/>workers (N=5)</li> </ol>                                   | Submitted to<br>Global Networks                               |
| <b>Chapter 5.</b> Capturing the Most<br>Significant Change after a work-<br>training program for community<br>health workers  | <ol> <li>What Most Significant Changes did community<br/>health workers experience as a consequence of<br/>following a work-training program?</li> <li>What are enabling and disabling factors to reach<br/>the Most Significant Changes according to these<br/>community health workers?</li> <li>What factors influence community health<br/>workers in the story selection of the most<br/>significant story?</li> </ol> | Most Significant Change<br>technique with qualitative<br>interviews and focus group                   | Phase 1) Individual interviews with<br>community health workers (N=9);<br>Phase 2) Focus group with<br>community health workers (N=7)  | Submitted to Social<br>Work in Health<br>Care                 |
| Chapter 6. Community health<br>workers and culturally competent<br>home care in Belgium: A realist<br>evaluation  | <ol> <li>Outcomes: What increase in the cultural competence of the home care organisations can be identified at the end of the 'Culturally sensitive care ambassadors' project?</li> <li>Mechanisms: How did the training contribute to the increased cultural competence of home care organisations?</li> <li>Context: Which factors and preconditions made the positive outcomes of the training more likely?</li> </ol>  | Qualitative interviews and<br>focus group with Context-<br>Mechanism-Outcome<br>configuration         | <ol> <li>Four focus groups with home care<br/>services, trainers, project<br/>coordinators and community health<br/>workers (N=25);</li> <li>Individual interviews with<br/>community health workers (N=10)</li> </ol> | Published in<br>Health and Social<br>Care in the<br>Community |

# CHAPTER 2. Methodological approach

#### CHAPTER 2. METHODOLOGICAL APPROACH

This chapter presents an overview of the methodological approach used in the different studies of the dissertation. Section 1 gives insight into the research paradigm and design underpinning this dissertation. Section 2 describes the data used for the studies, with data collection on live-in migrant care workers and on community health workers. Section 3 includes a positionality statement of the researcher.

#### 1 | RESEARCH PARADIGM AND DESIGN

This dissertation uses a qualitative research design, as it is aimed at deepening the understanding of alternative approaches in organising care for older adults. Qualitative research has a discovery focus and aims to contribute understanding and knowledge by reporting on phenomena within certain topics of interest. Further, "the purpose is to learn from the participants in a setting or a process the way they experience it, the meanings they put on it, and how they interpret what they experience, the researcher needs methods that will allow for discovery and do justice to their perceptions and the complexity of their interpretations" (Atieno, 2009, p. 16). Through qualitative research the meaning of people's lives in their real world is studied, representing their perspectives and identifying contextual conditions. Multiple perspectives about the topic of interest are acknowledged and are derived from those people who have personal experiences with the topic (Wu et al., 2016).

The research aim and corresponding methodology are inspired by a constructivist approach. Constructivism refers to "the understanding or meaning of phenomena, formed through participants and their subjective views" (Creswell & Clark, 2011, p. 40), in which reality is socially constructed and is subject to change. Constructivism starts from the theoretical perspective of interpretivism, which "makes an effort to 'get into the head of the subjects being studied' so to speak, and to understand and interpret what the subject is thinking or the meaning s/he is making of the context. Every effort is made to try to understand the viewpoint of the subject being observed, rather than the viewpoint of the observer" (Kivunja & Kuyini, 2017, p. 33). Reality is believed to be socially constructed and thus the emphasis lies on understanding individuals and their interpretation of the world around them. Only within a network of values are facts believed to have a meaning. Hence multiple realities exist and contextual factors are essential for creating and understanding knowledge. Also, research conclusions are contextually determined and cannot be merely generalised to every context. Accordingly, constructivist research – rather than universal laws – are more appropriate to understanding individuals (Guba & Lincoln, 1989).

As constructivism acknowledges that people construct meanings in different ways, this dissertation uses mainly narrative research as a methodology to investigate migrant care workers' and older adults' opinions based on their lived experiences. Since their experiences are subject to societal influences, the context in which these experiences became reality is crucial.

Within constructivist research, researcher and research reality are inevitably connected. The necessary collaboration between researcher and stakeholders is shown, as the research report is a 'joint construction' (Smaling, 2010). It is also acknowledged that "the researcher makes meaning of their data through their own thinking and cognitive processing of data informed by their interactions with participants. There is the understanding that the researcher will construct knowledge socially as a result of his or her personal experiences of the real life within the natural settings investigated" (Kivunja & Kuyini, 2017, p. 33).

#### 2 | DESCRIPTION OF THE DATA USED FOR THE DISSERTATION

This dissertation uses different qualitative research methods to answer the research questions. The data collection concerns live-in migrant care workers as well as community health workers. Chapter 3 is based on a qualitative interview study with older people and informal caregivers who hire live-in migrant care workers. Chapter 4 uses serial qualitative interviews with live-in migrant care workers to develop narrative collective vignettes. Chapter 5 applies the Most Significant Change technique using qualitative interviews and a focus group with community health workers. Chapter 6 is based on qualitative interviews with different stakeholders of a community health workers project and developed a context-mechanisms-outcomes configuration. Although it is described within the relevant chapters of this dissertation, a brief description of each methodology is provided below.

#### 2.1 | DATA COLLECTION ON LIVE-IN MIGRANT CARE WORKERS

The data on live-in migrant care workers were collected in two rounds: interviews with older people and informal caregivers, gathered by the researcher in 2016, and interviews with live-in migrant carers, collected in 2020-2021. For both rounds of data collection, the researcher made contacts to build a network that could help getting in contact with participants.

## 2.1.1 INTERVIEWS WITH OLDER PEOPLE AND INFORMAL CAREGIVERS WHO HIRE LIVE-IN MIGRANT CARERS

Chapter 3 is based on a qualitative study involving two types of participants: (1) older adults or their informal caregivers who hired live-in migrant care workers, and (2) professionals. Because older adults and informal caregivers with live-in migrant care workers are a hard-to-reach group and are often reluctant to be interviewed, eight individual interviews were conducted with older adults or informal caregivers. The preference was to interview the older adult rather than the family members, yet this was not always possible if the older adult had cognitive or health impairments. In addition, one focus group (N=6) and interviews (N=5) were conducted with medical and care-sector professionals who had been in contact with live-in migrant care workers. They were included in the study specifically on account of their knowledge and broader reflections on the live-in care sector. The questions asked aimed to capture older adults' perspectives on motivations to hire live-in migrant carers and their experiences. The criteria for inclusion of the older adults were being over the age of 60, living in Flanders or Brussels, and hiring a live-in migrant care worker (at the time of the interview or in the recent past). The interviews were conducted in Dutch or French, depending on the language of the participants, and were collected between January and March 2016. The guidelines of the Human Sciences Ethical Committee of Vrije Universiteit Brussel (VUB) were followed, in accordance with the European Framework for Research Ethics (European Commission Directorate-General for Research and Innovation, 2012).

#### 2.1.2 INTERVIEWS WITH LIVE-IN MIGRANT CARERS

Chapter 4 consists of a qualitative narrative study, with data collected from live-in migrant care workers and presented in collective vignettes. Live-in migrant care workers (N=10) were individually interviewed. In total 15 interviews were conducted, and five participants agreed to participate in a second interview. Through serial interviews participants were interviewed on multiple occasions, fostering familiarity and trust. In this way key topics were probed more than once and more in-depth

information can be gathered (Read, 2018). Some interview sessions with participants were timeconstrained due to limitations imposed by working hours and on-call duties, and therefore benefitted from an extra session. This second interview started with member check questions, in which analyses of single participants' data were discussed to obtain feedback from participants and add validity to the researchers' interpretations (Birt et al., 2016). The interview further focused in-depth on the experiences of the live-in migrant carers. Interviews were conducted in French, English or Spanish, depending on the language spoken by the participant. One interview was conducted with an Italian-Dutch interpreter. Because of social restrictions imposed in light of the coronavirus pandemic, the interviews were conducted online. One interview was conducted by e-mail. The interviews took place between November 2020 and March 2021.

#### 2.2 | DATA COLLECTION ON COMMUNITY HEALTH WORKERS

The data collected on community health workers was based on the specific case of an innovative work-training programme for community health workers in Brussels. This training programme was developed by a local NGO, EVA bxl, as part of the project 'Culturally sensitive care ambassadors valorising talents +' (2016-2021), financed by the European Social Fund (project ID 6044) and European Social Fund Transnational (project ID 7418). As a research institute we were partners in the project, starting from writing the project's application up to the dissemination of the lessons learned. The project addressed three urban challenges in deprived areas of Brussels: 1) migrant families living in a neighbourhood excluded from care services; 2) home care services operating in a neighbourhood lacking culturally competent care and outreach programmes; and 3) neighbourhood residents with a migration background who face high unemployment yet often have invaluable expertise, but who are not hired by care organizations because of having disallowed educational certificates. Three editions were organised of the work-training programme (in 2017, 2019 and 2020). Each edition 10 different community health worker trainees participated. Each work-training program lasted nine months and consisted of courses on culturally competent care, communication, and Dutch language. Trainees also did an internship in care organisations during these nine months to gain practical experience and followed exchange workshops between community health workers and care professionals working in care organisations. Nine care organisations participated in the project. More information in Dutch or French can be found on the project's website (https://cultuursensitievezorg.evabxl.be).

2.2.1 INTERVIEWS WITH COMMUNITY HEALTH WORKERS, USING THE MOST SIGNIFICANT CHANGE TECHNIQUE

Chapter 5 is based on a qualitative study using the Most Significant Change technique (Davies & Dart, 2005). This evaluation technique allows gathering a rich description of changes and capturing unexpected changes. Outcomes that are personally valued by trainees are included in this technique (Choy & Lidstone, 2013). This study therefore included those participants who followed the training and who could best describe what worked for them (Tonkin et al., 2021). Community health workers of all three editions of the training programme were included in the data collection, which took place between June 2020 and January 2021. The study was conducted in conformity with the guidelines of the Human Sciences Ethical Committee of Vrije Universiteit Brussel (VUB) and the European Framework for Research Ethics (European Commission Directorate-General for

Research and Innovation, 2012). The first step of the Most Significant Change consisted of conducting individual interviews with the community health workers (N=9) to collect stories describing changes brought about by the training. These interviews were conducted online using WhatsApp videocall because of social restrictions imposed by the coronavirus pandemic. One participant did not feel comfortable with an online interview, so a face-to-face interview was organised respecting the COVID regulations in force at the time. Interviews were conducted in French, English or Dutch, depending on the language spoken by the participant; the researcher was proficient in all three languages. In the second step of the Most Significant Change technique, the most significant change story was selected. To this end, the nine stories coming from the individual interviews of the first step were written down as separate, concise narratives. These were subsequently debated in a focus group discussion (N=7) with community health workers and the most significant story was picked through a horizontal selection process. This process values participants' priorities and is therefore useful when the aim is to identify the impact on the participants themselves (Tonkin et al., 2021).

## 2.2.2 INTERVIEWS WITH PROJECT STAKEHOLDERS, USING CONTEXT-MECHANISMS-OUTCOMES CONFIGURATION

The qualitative study in Chapter 6 uses realist evaluation to address the questions of what works, how, for whom, and under which circumstances (Dalkin et al., 2015). The data include a multiple stakeholder perspective to understand the multiple perspectives on the project. Four participant groups were included through individual interviews and focus groups: (1) community health workers who followed the full training programme, (2) care employees who followed a 5-day training course on culturally competent care, (3) trainers from both training events, and (4) project coordinators from the participating home care organisations. These data were collected in April 2017 and October 2017, using individual interviews with community health workers halfway through their training and focus groups with the four participant groups (N = 25) at the end of the training. Both the interviews and the focus groups were conducted in Dutch, French or English at the premises of a local NGO. Two participants who could not attend the focus groups were engaged in an email interview (Burns, 2010). Based on previous literature and the collected data, a context-mechanisms-outcomes configuration was developed throughout the study (Dalkin et al., 2015; Pawson & Tilley, 1997). The guidelines of the Human Sciences Ethics Committee of Vrije Universiteit Brussel, respecting the European Framework for Research Ethics (European Commission Directorate-General for Research and Innovation, 2012), were applied to this study.

#### 3 | POSITIONALITY STATEMENT OF THE RESEARCHER

As stated above, within constructivist research the researcher and the research reality are interconnected, and data gain meaning trough the interaction with participants and the personal experiences of the researcher (Kivunja & Kuyini, 2017; Smaling, 2010). Accordingly, this research was created under the influence of the researcher's individual values and beliefs, which are shaped by factors like education, religion, ethnicity, gender and social values (Darwin Holmes, 2020). In this section, reflections will be shared illustrating the significance of positionality of the researcher and potential effects on establishing, conducting and reporting the research. Because these reflections are personal, this part is written in the first person.

My background as a person and researcher in relation to the participants, as well as the used methodologies, have some consequences for the research. Concerning the methodologies, the four studies are driven by a strong intention to give a voice to the participants. Qualitative research is especially useful "to learn about the voices of marginalized persons, understand the thoughts and processes that people engage with in their everyday lives, and potentially develop theory" (Phoenix, 2018, p. 81). The emphasis in this research lies on the narratives of the interviewees. To preserve their active voice and authenticity in reporting the findings, direct quotes from the interview transcripts were preserved as much as possible. This research also makes use of different participatory techniques such as Most Significant Change and member check interviews, which require more and deeper involvement of participants than traditional research methods (Wilder & Walpole, 2008). During member check interviews, for instance, analyses of single participants' data were discussed to obtain feedback and add validity to our interpretations (Birt et al., 2016).

These two aspects (giving voice and working participatorily) could only work in a respectful relationship between the participants and myself as researcher. When discussing this relationship, I cannot ignore the current debate on being an insider vs. outsider in research. This debate mainly concerns who is best positioned to gather and present information accurately and truthfully (Darwin Holmes, 2020). Insiders are defined as "the members of specified groups and collectives or occupants of specified social statuses; Outsiders are the non-members" (Merton, 1972, p. 21). An outsider is further specified as someone without prior intimate knowledge of the group (Darwin Holmes, 2020). While the group of participants in this research was diverse and heterogeneous, I can define myself as an outsider, by lacking a migration background, having a residence permit, having a secure income, having a certified academic degree, etc. At the same time, I did not feel that our different experiences in life limited the interviews. In order to share meaningful information, I experienced it as more important to be transparent about my intentions as a researcher, to be respectful of participants' experiences, and to be open to their questions too. This reflection was also experienced by Dwyer and Buckle (2009, p. 59), who argue that "one does not have to be a member of the group being studied to appreciate and adequately represent the experience of the participants. Instead, we posit that the core ingredient is not insider or outsider status but an ability to be open, authentic, honest, deeply interested in the experience of one's research participants, and committed to accurately and adequately representing their experience." Other researchers (e.g. Darwin Holmes, 2020; Mercer, 2007) argue that the opposite of insiders and outsiders are rather artificial constructs, and question the clear dichotomy between the two concepts. So both positions can be experienced as a continuum in which the role of the researcher fluctuates. An interview with a live-in migrant carer illustrates this fluctuation between insider and outsider. For instance, I would be perceived by a participant as an outsider when talking about her migration trajectory, an experience I did not go through myself. However, when talking about the common neighbourhood in Brussels we both lived in, I would be perceived as an insider during that same interview.

Additionally, since the vast majority of participants were women, I experienced being a female researcher as an advantage. As Finch (1993) argued, having the same gender socialisation reduces social distance and facilitates dialogue. I felt that the participants were open about their experiences and were happy to have the opportunity to share their story. Some felt honoured that I was interested in their particular story. This experience is shared by Cotterill (1992), who describes her interviews as almost therapeutic for her participants because they had few other social contacts and were happy

with the opportunity to talk. I took on the role of active listener, by expressing emotion and reacting to their story. This stimulated a connection and encouraged participants to share experiences.

One way to counter a possible outsider effect was to conduct the interviews in the languages the participants felt most comfortable in, so they would be more at ease. This entailed interviewing in Dutch, English, French, Spanish or Italian. As I could understand Spanish but not speak it fluently enough to conduct an interview, I was assisted by a Spanish-speaking MSc student trained in the research methodology and topic. The one Italian interview was conducted with an interpreter. As for Dutch, French and English, I am proficient enough in them to conduct interviews.

Another way of countering possible outsider effects was by conducting serial interviews. Participants were interviewed on multiple occasions. This fostered familiarity and trust, making them feel more comfortable to share experiences (Read, 2018). Darwin Holmes (2020) argues that thanks to this familiarity, the participant might start seeing the interviewer as an insider. With other interviewees the relationship of trust was handed over to us by a local NGO who they already trusted and where they followed their training. To set a date for an interview, messaging through WhatsApp or Facebook was sometimes used. This more informal mode of contact allowed participants to also learn more about me as a researcher and share additional information outside the interviews. While this information was not included in the data collection, I could ask questions related to this previously shared information during a next interview.

## CHAPTER 3. HIRING LIVE-IN MIGRANT CARE WORKERS: MOTIVATIONS AND EXPERIENCES OF OLDER PEOPLE AND THEIR FAMILIES

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## CHAPTER 3. HIRING LIVE-IN MIGRANT CARE WORKERS: MOTIVATIONS AND EXPERIENCES OF OLDER PEOPLE AND THEIR FAMILIES

#### ABSTRACT

The increasing number of older people has a significant impact on the organisation of care in European countries. Formal care services face several limitations, while informal care is decreasing. As a result, older adults search for alternative strategies to meet their care needs. A recent tendency is to hire live-in migrant care workers. This study explores the motivations for and experiences of hiring live-in migrant care workers in Belgium of older people and their families. Using a qualitative study, eight in-depth interviews were conducted with older people or family members who had hired live-in migrant care workers. Additionally, five individual interviews and one focus group (N=6) with professionals were conducted. Data were thematically analysed, using both deductive and inductive approaches. The main motivations for hiring live-in migrant carers were shortages in the accessibility and availability of formal care service provision and the anticipated benefits offered by live-in carers (i.e. reducing informal carer workloads, guaranteeing person-centred and continuous care, the possibility of ageing in place and delaying entry into residential care). Older people had generally positive experiences of the care provided, both in terms of the task responsibilities and the quality of care. The findings indicate that live-in migrant care workers can meet the demands of person-centred care at home. However, a clear hierarchy between older adults and care providers was identified and questions were raised about the training, insecure employment conditions and legal status of live-in migrant care workers.

#### KEY WORDS

Live-in migrant care worker, Long-term care, Domiciliary care, Older people

#### 1 I INTRODUCTION

As is the case in other European countries, Belgian public policy places an emphasis on community care. Policy on community care is understood as the shift in care to enable people with disabilities, the chronically ill, frail older people, young people with behavioural and emotional problems, people living in poverty, and others, to take their place in society, to support them where necessary and to integrate care into society as far as possible (Strategische Adviesraad Welzijn Gezondheid Strategische Adviesraad Welzijn Gezondheid Gezin, 2012, p. 8). Whereas initially, there was a deliberate shift from residential care to care provided in individual's homes and thus in the community (deinstitutionalisation of care), more recently, there has been a shift from care in the community to care provided by the community (Genet et al., 2011). This means that the focus is no longer only on formal care organisations but that informal care, neighbourly help, self-care, etc. also play a significant role in community care. However, community care faces several challenges. First, the provision of informal care is decreasing (Colombo et al., 2011) due to changes in family structures (Hoff, 2015). Second, home care services are often limited to providing integrated and person-centred care (Nies, 2015); they may operate in a highly fragmented manner and face budgetary restrictions (Pacolet & De Wispelaere, 2018). In response to these informal and formal care gaps, older people are turning to creative solutions, one of which is to employ live-in migrant care workers (Anderson, 2012). These care workers often provide more affordable long-term care in the older adult's home compared with 24-hour care provided by national health care providers (Lamura et al., 2013; Schwiter et al., 2018). The prices for live-in migrant care workers, however, can differ widely depending on how the carers are employed (i.e. through an agency or directly by the family). Live-in migrant care workers are generally defined as: "informal carers, usually women from third countries who are privately employed by the older person or by their family members to meet the needs for domiciliary support and care" (Di Santo & Ceruzzi, 2010, p. 4).

At present, the situation of live-in migrant care workers is the focus of research in Italy (e.g. Cangiano, 2014; Lamura et al., 2013) and to a lesser extent in Austria (e.g. Schmidt et al., 2016), Canada (e.g. Bourgeault et al., 2010; Chowdhury & Gutman, 2012), Israel (e.g. Ayalon & Roziner, 2016; Cohen-Mansfield et al., 2017; Halperin, 2019), Spain (e.g. De La Cuesta-Benjumea & Roe, 2014), and Taiwan (e.g. Chou et al., 2014; Liang, 2018). In Southern European countries, research on the employment of migrant care workers in the long-term care of older adults mostly focuses on live-in carers in private households, while that in Northern and Western Europe focuses on migrant carers who are officially employed in formal healthcare organisations, such as home care services, residential care centres and hospitals (Hoff, 2015; Munkejord, 2017; Theobald, 2017). However, some studies have been carried out, such as Da Roit and van Bochove (2017), Bruquetas-Callejo (2019) and van Bochove and zur Kleinsmiede (2021) in the Netherlands, Lutz and Palenga-Möllenbeck (2010) and Kniesjka (2018) in Germany, and Horn et al. (2021) providing a broader overview. At policy level, there is growing interest and recognition of this topic. For example, the European Economic and Social Committee concluded in 2018 that the growing shortage of carers requires urgent European Union regulation of the live-in care sector. However, to date, research on this topic in Belgium is scarce. The studies that exist by Safuta (2017) and Giordano (2017) focus on migrant domestic services in general, looking respectively at the personalisation processes of migrant workers, and the impact of care, gender and migration regimes on migrant domestic work. In this paper, we explore the motivations and experiences of older adults and their family members who hire live-in migrant care workers.

#### 2 | BACKGROUND

#### 2.1 | THE BELGIAN CARE REGIME

Belgian older adults can count on a well-developed system of social protection, including cash and in-kind benefits and care allowances. This system is multi-layered and governed by federal and regional policies (Pacolet & De Wispelaere, 2018). Of the over 65 population, 13.6% receive formal long-term care, of which 8.5% are in residential facilities and 5.1% are at home (i.e. home nursing). A further 20% of older people receive support from informal carers such as children, family or friends (Federal Public Service Health, 2019). The Belgian care system is characterised by a shift from residential care services to home services, resulting in community care with formal home care services, and an increasing focus on greater societal responsibility (Means et al., 2008). Since Belgium has a strong history of residential care provision, this shift ensured a reorganisation of the entire care chain with a consequent reallocation of investments (Giordano, 2017; Simonazzi, 2009). Several actions have been taken by the Flemish Government (Northern region of Belgium) in the Flemish senior citizens' policy plan 2015-2020 to enable older adults to remain at home for as long as possible (i.e. housing modifications, developing integrated care, promoting care from a network- and client-centred perspective and encouraging informal caregivers) (Flemish Government, 2015).

Additionally, Belgian care provision is traditionally oriented towards providing services rather than cash allowances (Giordano, 2017). Therefore, employment in the service provider organisations' model dominates Belgian home care, which means that a family is not the direct employer as there is a third party acting as intermediator. The care worker is employed by a public or private organisation (Farvaque, 2013). This model generally entails fewer risks than being employed directly by families in terms of the quality of services and working conditions (Giordano, 2017).

#### 2.2 | MOTIVATIONS TO HIRE LIVE-IN MIGRANT CARE WORKERS

While in some countries hiring a live-in migrant care worker seems an obvious and systematic solution (e.g. in Italy, one in four older adults with dementia is cared for by a live-in migrant care worker (Lamura et al., 2010)), in other countries including Belgium, it is still an uncommon practice. Research by Da Roit and van Bochove (2014) indicated that older adults who hired a live-in migrant care worker often needed constant care and assistance with most of their daily tasks. In this case, any informal resources often were already inadequate to meet these needs. Additionally, older adults and family members were sometimes not in favour of residential care services as demonstrated by research in Italy and the UK (Shutes & Chiatti, 2012; van Grafhorst, 2014). When an older person needed 24-hour care, a live-in migrant care worker was a possible addition to the care already provided (Shutes & Chiatti, 2012), although critical questions might rise on affordability (Schwiter et al., 2018), quality of care (Ayalon, 2009) and working conditions (Heng et al., 2019).

A primary motivation often referred to in the literature to hire a live-in migrant care worker is the individual's wish to live at home for as long as possible (Da Roit & van Bochove, 2014; Horn et

al., 2019; Lamura et al., 2013). Second, due to the flexibility and constant availability of live-in migrant care workers, continuous care can be guaranteed, meaning that this is provided by the same person (Davies & Mans, 2015; van Grafhorst, 2014). Last, the workload of informal carers is reduced (Horn et al., 2019; van Grafhorst, 2014).

#### 2.3 | EXPERIENCES WITH LIVE-IN MIGRANT CARE WORKERS

Da Roit and van Bochove (2014) indicate that older adults who hire a live-in migrant care worker often need constant care and help with most of their daily tasks. Therefore, live-in migrant care workers are recruited for different tasks that go beyond medical aspects, also including physical, social, psychological, financial and administrative tasks (van Grafhorst, 2014). Most of the time, they assist with the housekeeping and daily activities such as getting dressed and cooking. Often, they also provide companionship to reduce the social isolation of older adults (Lamura et al., 2013), thereby reducing a perceived lack of family support (Østbye et al., 2013). However, there are also studies claiming that the language barrier and age gap can result in a lack of social interaction, with the older adult experiencing feelings of loneliness (Ayalon, 2009; Walsh & Shutes, 2013). Moreover, research suggests that the absence of a shared cultural outlook can undermine the formation of a good caring relationship (Walsh & O'Shea, 2010) due to concerns about difficulties with understanding and being understood (Manthorpe et al., 2012). Nonetheless, research in Israel identified that affective relationships could develop in spite of language differences and that similarities in personal qualities and cultural background are more important indicators (Porat & Iecovich, 2010). Teshuva et al. (2019) identified that positive care relationships between care receivers and live-in migrant care workers are the result of an emotional connection, reciprocity, good communication and that the older person's care needs are met. Furthermore, family dynamics are experienced in different ways with the presence of a live-in carer (Salami et al., 2017). The home, for example, is turned into a workplace and older adults have to be able to adapt to less privacy and to living with a stranger in their house (Da Roit & van Bochove, 2014). Several studies have found that older adults with live-in carers experienced positive health outcomes (Ayalon, 2011; Østbye et al., 2013; Porat & Iecovich, 2010). These result from the wide availability of live-in carers who provide round-the-clock care (Ayalon, 2009). In particular, instrumental support ensures better outcomes for health and for family carers, and less disruption of routines (Østbye et al., 2013).

Different approaches taken by countries towards employing live-in migrant care workers are evident. The majority of live-in migrant care workers in the Netherlands are recruited by agencies, while in Southern European countries, Germany and Austria, most live-in migrant care workers are employed directly by individual older adults (Da Roit & van Bochove, 2017; Kniejska, 2018). Within European countries, European employees do not need to apply for a work permit (van Grafhorst, 2014). By working in cooperation with organisations in the country of origin (Sarti & Scrinzi, 2010), migrant care workers obtain the status of 'posted workers', which means they are "employed in one EU member state but sent by their employer on a temporary basis to carry out work in another member state" (Snel et al., 2015, p. 521). When hired through agencies, many of the live-in migrant care workers are trained as nurses or nursing assistants (Da Roit & van Bochove, 2017). In addition, most receive training in older adult care in their country of origin or their destination country. Research by van Grafhorst (2014) in the Netherlands showed that most live-in migrant care workers

had previously worked as a nurse or carer and received 200 hours of training, in which they learned practical issues such as how to transfer someone from a wheelchair to a bed, and how to assist with feeding. Dutch agencies offer their workers three to four supplementary training programmes a year (van Grafhorst, 2014). However, research showed that live-in migrant care workers still are not adequately trained to perform the diverse range of tasks. The vast majority learns the necessary skills from family caregivers on the job (Gordolan & Lalani, 2009). According to some agencies, being trained in the care of older people was not of primary importance; instead, the work experience, mindset and personality of the live-in carer (e.g. are they a hard worker, committed or of cheerful character) are the essential requirements for providing suitable care (Huang et al., 2012; Lovelock & Martin, 2016).

#### 3 | RESEARCH AIMS

This paper aims to address two research gaps. First, studies in Western European countries focus mainly on migrant care workers in formal home care organisations, so that research on live-in migrant care workers is lacking, being mainly limited to Southern European countries, where the care regime is radically different from the situation in Belgium. Furthermore, qualitative studies focus mainly on the experiences of care workers (e.g. Da Roit & van Bochove, 2014; Heng et al., 2019; van Grafhorst, 2014). In 2017 Salami et al. pointed out in their review study that few studies addressed perspectives of families and care receivers of live-in migrant care workers. Furthermore, Schwiter et al. (2018) argued that the existing literature was mainly focusing on the perspective of care workers and the challenges they are facing. In the meantime, Horn et al. (2019; 2021) included the perspective of care receivers in their studies. However, in Belgium this perspective is still lacking. Salami et al. (2017) nevertheless argued that the perspective of older adults and their families need to be investigated to improve relationships with live-in migrant care workers and prevent mistreatment. Additionally, this will help policy makers in adequately addressing care needs of older adults. Therefore, the overall purpose of this study is to obtain insight into the experiences of older people and their families in Belgium who receive care from a live-in migrant care worker.

The following research questions are addressed:

- Research question 1: What are the motivations of older adults and their families to hire a live-in migrant care worker?
- Research question 2: How do older adults and their families experience the presence and care of a live-in migrant care worker?

#### 4 | METHODS

#### 4.1 | DATA COLLECTION

This study used a qualitative approach involving two types of participants: (1) older adults or their informal caregivers who hired live-in migrant care workers participated in individual interviews, and (2) professionals participated in either a focus group or individual interviews. Older people and informal caregivers with live-in migrant care workers are a hard-to-reach population and are often reluctant to be interviewed. This is linked to the sometimes precarious legal situation of employing a

live-in migrant care worker, as there is no clear regulatory framework concerning their work permits and conditions. Therefore, it was decided to include the views of professionals as additional information to answer the research questions. These were professionals whose jobs involved contact with older people who relied on live-in migrant care workers; they ranged from healthcare employees in the field to managers and policy staff (see Table 3 for more details). The questions asked aimed to capture the older adults' perspectives.

Individual interviews (N=8) were conducted with older adults or their family members and provided information about nine older adults (one interview included a married couple). The preference was to interview the older adult rather than the family members, however, this was not always possible if the older adult had cognitive or health impairments. Therefore, one interview was conducted with an older adult alone, two with older adults in the presence of their informal caregiver (i.e. partner or child), and five with informal caregivers. The criteria for inclusion of the older adults were that they were over the age of 60, living in Flanders or Brussels, and hiring a live-in migrant care worker (at the time of the interview or in the recent past). These participants were recruited through various agencies engaged with live-in migrant care workers, religious organisations, ethnic and cultural organisations, private contacts and snowball sampling. An overview of the participants can be found in Table 2. The age of the older adults included in the study (through direct interviews or indirectly through interviewing their informal caregiver) ranged from 60 to 88, with a mean age of 80 years (SD=9.4). Both male (N=4) and female (N=5) older adults were included in the research and the majority were married (N=6). Interviews were conducted in convenient places chosen by participants, mostly in their homes, and lasted from 20 to 80 minutes. They were collected between January and March 2016 in Flanders and Brussels (two regions of Belgium). The interviews were conducted in Dutch or French depending on which language the participants felt most comfortable to converse in.

|             | Gender of<br>older adult | Age of<br>older adult | Marital status<br>of older adult | Country of live-in<br>migrant care worker | Type of<br>employment | Interviewee                  |
|-------------|--------------------------|-----------------------|----------------------------------|---|-----------------------|------------------------------|
| Interview 1 | Male                     | 70                    | Married                          | Poland                                    | Private               | Son                          |
| Interview 2 | Male                     | 60                    | Married                          | Philippines                               | Private               | Older person<br>and partner  |
| Interview 3 | Male                     | 87                    | Married                          | Bulgaria                                  | Private               | Partner                      |
| Interview 4 | Male and<br>Female       | 86 and 88             | Married                          | Bulgaria                                  | Agency                | Daughter                     |
| Interview 5 | Female                   | 80                    | Widow                            | Iran                                      | Private               | Older person                 |
| Interview 6 | Female                   | 81                    | Married                          | Poland                                    | Agency                | Partner                      |
| Interview 7 | Female                   | 85                    | Widow                            | Poland                                    | Agency                | Older person<br>and daughter |
| Interview 8 | Female                   | 85                    | Married                          | Bulgaria                                  | Agency                | Daughter                     |

TABLE 2 Overview of individual interviews with older adults

Additionally, a focus group interview with six health professionals was organised. This explored the situations of older adults with a live-in migrant care worker. The participants were either medical professionals or were involved in the care sector as staff members (see Table 2) and had been in contact with people cared for by a live-in migrant care worker. The participants were recruited through organisations in the care sector and by snowball sampling. They were included in the study specifically on account of their knowledge and broader reflections on the live-in care sector. However, they were asked questions that would capture the perspectives of older adults. The duration of the focus group interview was 110 minutes and the language spoken was Dutch. In addition, five health professionals and staff members were individually interviewed for several reasons, such as their lack of availability at the time of the focus group or that they spoke another language (i.e. French). These professionals had been in care situations where a live-in migrant care worker was present (see Table 2 for an overview). The interviews lasted between 25 and 60 minutes.

|               | Gender | Profession  |
|---------------|--------|---|
| Focus group 1 | Female | Occupational therapist                            |
| Focus group 1 | Female | Researcher on domestic work                       |
| Focus group 1 | Female | Staff member, organisation for solidarity economy |
| Focus group 1 | Female | Staff member, expertise centre on care            |
| Focus group 1 | Male   | General practitioner                              |
| Focus group 1 | Male   | General practitioner                              |
| Interview 1   | Male   | Staff member, home care service                   |
| Interview 2   | Male   | Researcher on transnational mobility              |
| Interview 3   | Male   | Home health nurse                                 |
| Interview 4   | Female | Staff member live-in care agency                  |
| Interview 5   | Female | Policy staff on healthcare employment             |
|               |        |   |

TABLE 3 Overview of focus group and individual interviews with professionals

#### 4.2 | INTERVIEW SCHEME

The interview questions for the older adults and their informal caregivers included four topics: (a) the motivations of the older adult to employ a live-in migrant care worker; (b) experiences of the recruitment process of a live-in migrant care worker; (c) experiences of the care situation; and (d) the expectations of the older adults. The interview questions for health professionals and staff members focused on four additional topics: (e) the profile of the older person and the live-in migrant care worker; (f) the advantages and disadvantages of receiving care from a live-in migrant care worker; (g) the quality of care; and (h) the regulations regarding live-in migrant care work. These themes were determined by drawing on previous literature in the field of live-in migrant care work (as described in the literature review).

#### 4.3 | ETHICAL CONSIDERATIONS

The study was conducted according to the ethical guidelines of the Declaration of Helsinki (2013). A team of researchers, together with the authors, reflected on the process of the research and any potential harm and discomfort arising from it. An informed consent document set out the details of the study to the participants, including its broader objectives, their right to withdraw at any time, data governance and information on confidentiality. All participants gave both written and verbal consent for an audio-recorded interview. To ensure confidentiality, participants were coded in the data analysis process and identifiable information was altered, e.g. names and place names were removed.

#### 4.4 | DATA ANALYSIS

The interviews and focus group were audio-recorded and transcribed verbatim. The data were analysed using the software program MAXQDA. To identify, analyse and report on the data, the thematic analysis procedure by Braun and Clarke (2006) was followed. It consisted of: 1) becoming familiar with the data; 2) generating initial codes (depending on data and theory); 3) searching for themes; 4) reviewing themes; 5) defining and naming themes; and 6) writing up the report (Braun & Clarke, 2006). This procedure allowed the authors to conduct both deductive (i.e. theory-driven) as well as inductive (i.e. data-driven) analysis (Fereday & Muir-Cochrane, 2006). The analysis was carried out by the first author, in close collaboration and through regular consultation meetings with the second author. For this paper, interview quotations have been translated into English by the authors. All names in the quotations have been replaced with fictitious names.

#### 5 | RESULTS

Based on the research questions, different themes emerged from the data. The first theme relates to (1) the motivations of the older adults and their informal caregivers. The other themes relate to (2) the experiences arising from the presence and care of a live-in migrant care worker: (a) perspectives on task responsibilities and corresponding training; (b) perceptions of employment strategies and working conditions; and (c) experiences of the relationship between the older adult and live-in migrant carer.

5.1 | MOTIVATIONS OF OLDER ADULTS AND INFORMAL CAREGIVERS

The participants gave different reasons for their decisions to hire a live-in migrant care worker, as shown in the motivation triangle (see Figure 5). These motivations are discussed in detail below.

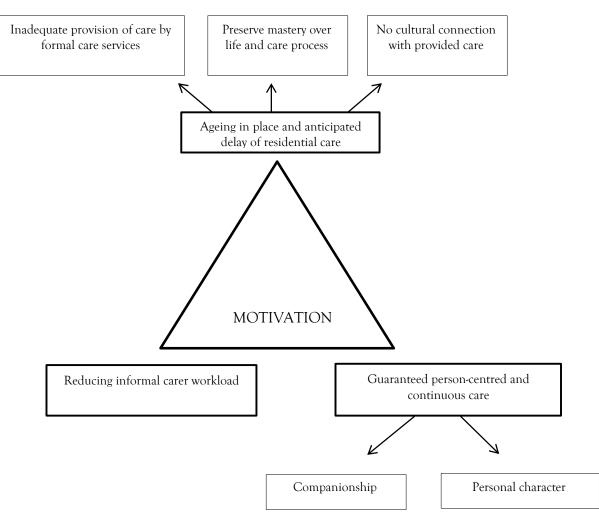


FIGURE 5 Motivation triangle of care receivers to hire a live-in migrant care worker

A primary motivation of participants was that the presence of a live-in carer made *ageing in place possible and delayed residential care.* Living in a familiar environment was invaluable to the older adults and their informal caregivers. The partner of an older adult expressed this as follows: 'Home is *incredibly important for us.* When we built our house, we said "this is our senior apartment". This is where we want to grow old' (Partner of 81-year-old woman). Partners also argued that it was crucial for them to spend as much time as possible with their dependent spouses at home; this was only possible with the help and support of extensive home care as they could no longer cope on their own. One participant explained that he felt lonely when his wife stayed in a care home and that he felt sorry for her. Therefore, he decided to look for a live-in carer so his wife could return home: 'Because, first of all, I could not see her without feeling sorry for her. You had to see her sitting there in the care home. I really pitied her and also myself. (...) So, it's also a bit selfish because I didn't want to be alone' (Partner of 81-year-old woman).

Both older adults and health professionals indicated that organising older adults' care within the available formal care services was inadequate. They pointed out the lack of suitable and sufficient formal support to provide care at home. If older adults wanted to obtain the necessary support within the regular care system, they had to rely on different care services for different tasks. Due to this fragmentation of regular care services, the majority of the participants in this study preferred the

presence of a live-in carer who combined different tasks and thus facilitated their situation. In some families, a live-in migrant care worker replaced a housekeeper, nurse etc., while in other families they took complementary roles. A staff member illustrated the diversity of tasks they could do:

'I think the difficulty is, for example, that all the home care services are provided by different actors. So, for the older person, it is sometimes complicated. They see the nurse in the morning, the housekeeper, the cleaning lady, the physiotherapist, the general practitioner... So, if you have a live-in carer, you have the same person to do everything [however, a live-in carer will not do the work of a physiotherapist or general practitioner]. It is a secure and discrete relationship too. They can think: 'When I need something, I can call her and she is there. She is always there" (Staff member, home care service).

Another factor that increased the motivation for ageing in place was that older adults or their family members wanted to have a voice in the care arrangements and *preserve mastery over their lives and care process*, instead of being passive care receivers. According to them, the permanent presence of live-in migrant care workers responded to these concerns and ensured that they remained in control of their lives. Furthermore, participants indicated that formal care organisations decided on the timing of house calls and the amount of time spent on each care task due to their tight schedules. However, this meant that the older adults would constantly have to arrange their daily lives around the schedule of the care professionals:

'At first, we tried to arrange it with the classic offer of home care, nurses, and so on. But my mother found the situation with formal home care services very difficult, in the sense that they had to provide the service at very precise hours. And that had a heavy impact on their lives. For example, my father had to go to bed at 7 p.m., because that was the time the nurse could be there. So, in fact, their whole life was arranged around the professional home care and not the other way around' (Son of 70-year-old man).

Nevertheless, most of the older adults would have preferred to hire a Belgian caregiver, but none of the participants found anyone willing to reside in their home at an affordable cost. Participants indicated that foreign caregivers were more willing to work for a lower wage compared to Belgian standards. For this reason, the older adults felt forced to look for a foreign caregiver.

Several health professionals argued that some families could not make a *cultural connection with the formally provided care.* In particular, cultural preferences played a role in whether moving into residential facilities was considered to be a valuable option within a community. Some participants indicated that residing in a nursing home was considered taboo, for example in Islamic and Jewish communities. Also, these communities were afraid that the care institutions would not meet their religious practices (e.g. dietary prohibitions) or their wishes and needs as a family. These factors strengthened their wish for a live-in carer, as illustrated by a home health nurse: 'They also want to have the feeling of having some control over what happens with their father or mother. While in a hospital or nursing home, you actually give more power to the institution. And then you have to go along with the visiting hours etc.' (Home health nurse).

A second motivation, particularly according to health professionals and informal carers, was to *reduce the informal carer's workload*. Some informal caregivers searched for alternatives to allow themselves to have some time off. One interviewee explained that it was the general practitioner who recommended she find additional help to take care of her husband:

'The general practitioner wouldn't allow my husband to come home unless there was round-the-clock support. I was already taking care of him for the past three and a half years. I was really doing it on my

own, without the help of anyone, except my cleaning lady and he [the general practitioner] said it was irresponsible, given my age' (Partner of 87-year-old man).

The third motivation, guaranteed person-centred and continuous care, was often quoted as being important. This was highlighted by the informal caregivers as it reassured them that someone would be present to always take care of their parents. The daughter of a care-dependent couple clarified this as follows: 'So that the people can be taken care of at home and that the family can be at ease. The family can live in a different way. We were always anxious before: "I hope they didn't fall; I hope nothing bad happened" (Daughter of 86- and 88-year-old man and woman).

Participants were convinced that these live-in carers were better suited than other care services to meet the needs of older adults because they were part of their daily lives, as mentioned by the same daughter: 'They (older parents) can live at their own rhythm. Because, for example, it takes my dad very long to eat and because of her [live-in carer] presence, he can have his dinner for more than 1 hour. This would not be possible in a care home due to the strict schedule they have' (Daughter of 86- and 88-year-old man and woman).

Some older adults and family members also expressed the need for a live-in carer to keep them *company*. A trusting relationship could be built, which made the older person able to cope with feelings of loneliness. Many participants appreciated the 'familiar' *personal character* of how the care was provided. In some cases, the live-in carer was considered as part of the family.

#### 5.2 | OLDER ADULTS' AND INFORMAL CAREGIVERS' EXPERIENCES OF THE PRESENCE AND CARE OF LIVE-IN MIGRANT CARE WORKERS

To identify the experiences of older adults with live-in migrant care workers, participants were asked about the global care situation: perspectives on task responsibilities and corresponding training, perceptions of employment strategies and working conditions, and experiences of the relationship between an older adult and live-in migrant carer.

#### 5.2.1 PERSPECTIVES ON TASK RESPONSIBILITIES AND CORRESPONDING TRAINING

Participants viewed the role of a live-in migrant care worker as consisting of a variety of tasks. The main tasks they were expected to do were preparing dinner, washing, ironing, collecting groceries, taking care of the garden, administering medication and providing companionship for the older adults. A few live-in migrant care workers provided transport for the older adults to locations outside the home. Besides the presence of a live-in carer, several older people additionally received services from meals on wheels, cleaners, home nurses, etc.

In terms of education, the agency participating in this study, which recruited the live-in carers, organised training programmes in the country of origin for those who did not have any previous background in caring. The participants felt that the live-in migrant care workers learned 'the basics of nursing' during this training, although they did not think this was entirely consistent with the tasks they then had to perform. The agency believed that care experience was more important than training. The daughter of a care-receiving couple explained what in her opinion were the qualities a live-in carer needed to have: 'Of course they have to be able to deal well with older people with illnesses, have empathy, do a bit of housekeeping, be friendly to the older people, this is very important, and reassuring for the family' (Daughter of 86 and 88-year-old man and woman). Furthermore, participants who did not contact a

care provider to hire a live-in carer knew that the carers often lacked training for this job. Therefore, family members took responsibility to show the carer how to do certain tasks, as a partner explained: 'He has no medical knowledge. That in itself is the problem. I have trained him as far as I could. But the initiative has to come from him and there's not much there' (Partner of 60-year-old man). Even though most participants were satisfied with the quality of care, some experienced a lack of training.

#### 5.2.2 PERCEPTIONS OF EMPLOYMENT STRATEGIES AND WORKING CONDITIONS

Most older adults had positive experiences of the employment strategies and did not question the working conditions of carers, especially when relying on an agency. They paid the agency and the agency paid the carer. However, many of the older participants experienced the cost of a carer as a financial burden, since the monthly charge was between 2200 and 3500 euros. For this amount, the live-in carers were available 24 hours a day, with 1 day off per week. The carers were entitled to holiday leave and in cases of absence, the agency provided the option of a replacement. Sometimes family members themselves provided this replacement, as a change in carers was often experienced as a difficulty. The live-in migrant care workers did not have a fixed schedule; instead, this depended on the daily tasks that needed to be done. For most of the participants, the live-in carer stayed approximately 6 months and often was then replaced by the agency. Nevertheless, some older adults questioned the legal status and employment conditions of live-in migrant care workers:

'In fact, in the beginning I was against this care employment. I thought it was impossible because it was a person who gave up her freedom completely. She had to be available for 7 days, 24 hours to take care of my father. I thought it was almost slavery. But at the same time, it has been experienced by Linda (live-in carer) as an improvement in her situation' (Son of 70-year-old man).

A policy staff added the following comment on employment conditions:

'It depends on which circuit they enter into, how they regulate it. Of course, if it's through organisations that just bring people in contact with older adults, if they don't ask for subsidies, how can we know what happens in the house next-door? So, you can't actually control that. It is a different story if they appeal to subsidies or if they need to issue work permits. But that remains the question. We are worried about the labour law. How is this regulated, and for what job are they coming? And if they do the job, do they have the right papers?' (Policy staff).

Some participants did not work together with an agency but employed a live-in migrant care worker on a private basis. They came into contact with the carer through personal contacts or online advertisements, for example. Children often played a substantive role in arranging the practical aspects. In most cases, there was only a verbal agreement rather than a written contract. Therefore, a concrete description of the role and daily tasks of the live-in carer was frequently lacking. The older adults directly paid the live-in migrant care worker between 750 to 1500 euros per month. The duration of stay of the carers varied among the participants, ranging from 2 months to 5 years or even longer. Given the vagueness of the terms of employment, some of the live-in carers did not have a (fixed) day off. An interviewe explained that some live-in carers developed a system themselves: 'They make arrangements with their sister for example in Poland. "I will work for 2 months and then I will return home and look after my sister's children". Actually, they have developed their own system' (Staff member, organisation for solidarity economy).

5.2.3 EXPERIENCES OF THE RELATIONSHIP BETWEEN OLDER ADULT AND LIVE-IN MIGRANT CARER

A good relationship between the carer and older adult was highly appreciated. Language difficulties were not often mentioned by the participants, as most of the carers spoke the basics of a common language with the care receiver or were learning a new language: 'My parents can speak English and German. And that lady also spoke German, so yes, it was actually German and English, that went well. And she was very eager to learn Dutch, because now she speaks Dutch fluently' (Daughter of 85-year-old woman). Other forms of communication were thought to be even more important, such as being attentive, patient, friendly and compassionate, as an older adult's partner put it: 'She almost has to be friends with the patient. Very compassionate, and she really is. Not pretending, but she simply is' (Partner of 81-year-old woman). However, several older adults reported experiencing less privacy and had to get used to the presence of the live-in carer and the handling of power and control. This was especially the case for the partners: 'I said to her (live-in carer): "Listen, you have to deal with me and I am the boss here. My husband cannot be the boss anymore". (...) And she replied, "Yes that is good". And now we have a certain routine, but that took us several weeks' (Partner of 87-year-old man). In general, after a few weeks, older adults and their partners found a good balance in the relationship and even started to see the live-in carers as family members: 'She is part of our family. We celebrate her birthday and at Christmas she also receives a gift' (85-year-old woman). Even after the care situation had ended, some family members remained in contact with the live-in migrant care worker. Nevertheless, the son of an older adult explained that even though his mother and the live-in migrant care worker got along well, a hierarchy remained between them:

'The solidarity between those two women [the live-in carer and the wife of the care receiver] who had to take care of the same man, my dad, was huge and they became very close of course. What was left afterwards was a very close friendship. But at the same time, my mother called her [the live-in migrant care worker] Linda, and Linda called her madam. Which means a lot' (Son of 70-year-old man).

#### 6 | DISCUSSION

## 6.1 | INSIGHTS INTO THE MOTIVATIONS OF OLDER PEOPLE AND THEIR FAMILY MEMBERS

To address the first research question on motivations, this study provides a triangle of motivations of older adults and their family members to hire live-in migrant care workers. First, livein migrant care workers made it possible to age in place and to delay the start of residential care. The desire to age in place was not only expressed by older adults but was also shared by their partners and other family members, who wanted to postpone the move into a care or nursing home for as long as possible. This finding is supported by previous research carried out by Lamura et al. (2010), who found this to be one of the main motivations for Italian families. To be able to stay at home, these older adults needed round-the-clock care. At present, formal home care services do not meet the needs of 24-hour care, which makes it challenging for frail older adults valued being cared for by one single person rather than different actors. As previous research by Russell et al. (2011) showed, personnel continuity in home health care may reduce hospitalisation and increase functioning in daily activities. It also makes the older adult feel calmer and more balanced (Horn et al., 2019). A crucial factor is having a voice in these care arrangements and retaining autonomy over their lives. This study demonstrates that cultural preferences concerning care also play a role, as confirmed in studies by Horn et al. (2019) and Halperin (2019), which stressed the often negative associations with residential care homes in different cultures.

Second, by hiring a live-in carer, the workload of family carers can be reduced (Lamura et al., 2019). Shutes and Chiatti (2012) found that the 'care potential' of family carers within families that employed live-in carers was often exhausted. The older adults and their relatives indicated in this research that they had more quality time together, as live-in carers also provided indirect support for family carers (Halperin, 2019).

Lastly, the triangle of motivation contains the guarantee of person-centred and continuous care. Family members found it reassuring to know that their relatives were always with someone (van Grafhorst, 2014). The personal character of the carer was appreciated, since the live-in carer could adapt the care to the daily lives of the older adult. This made possible the development of a trusting relationship, whereby the specific needs of the older person were considered by the live-in carer so that person-centred care could be provided. The importance of trust in caring relationships has also been highlighted by previous studies (Williamson, 2007).

## 6.2 | INSIGHTS INTO THE EXPERIENCES OF OLDER PEOPLE AND THEIR FAMILY MEMBERS

To address the second research question, different experiences of the presence and care of livein migrant care workers were identified. First, the task responsibilities of live-in migrant care workers were found to be very broad, while their training was often perceived to be insufficient. Family carers played an important role in teaching specific tasks; this was also shown in research by Kniejska (2018) on live-in migrant care workers in Germany. Second, questions about employment conditions were raised by some participants, such as the lack of a written contract in several cases and no firm description of the role and tasks. These concerns are confirmed by Heng et al. (2019), who described the limited solutions available for live-in migrant care workers to ensure sufficient rest during their caregiving obligations. Third, participants extensively discussed the relationships of power and control between the care receivers and caregivers. Even though a good and understanding relationship may exist between both parties, a hierarchy remained. This was manifested in the names they used for each other. While power relations within live-in care have been discussed previously (e.g. King-Dejardin, 2019; Liang, 2018), this literature mainly explored care situations where live-in care workers were either part of the family or were seen to be inferior and experienced unequal power relations. Our findings, however, show that within a single care situation the live-in migrant care worker could be seen as part of the family, while a hierarchy could remain in place. This is in line with the mixed perspective of Ayalon (2009) who described family-like interactions in households with round-theclock live-in migrant care workers, with older adults considering live-in carers to be part of their family. Nevertheless, she also shared the perspective of live-in carers, which was sometimes less positive, as they could feel they were treated like machines or slaves. Giordano (2017) defined these power relations and hierarchy by class, race, nationality and gender, and a feeling of superiority based on the employment relationship. The concept of servitude (Anderson, 2000) was recalled, as domestic work was characterised by a logic of servility and this justified a relationship based on superiority and inferiority (Giordano, 2017; King-Dejardin, 2019). Therefore, it is recommended that future research should focus on how these relations are shaped and how the different actors involved interact.

#### 6.3 | LIMITATIONS OF THE STUDY

Some limitations of the present study should be taken into consideration when interpreting the findings. First, a small sample of interviewees was used due to the difficulties (e.g. the sensitivity and secrecy of live-in migrant care workers) in recruiting this group. However, qualitative research does not aim to generalise but rather to describe in-depth experiences from the points of view of interviewees (Baarda & de Goede, 2013). Data saturation point was reached, meaning that additional data did not lead to new emerging themes as it tended to reinforce the findings of previous data (Saunders et al., 2018). In addition, previous studies have been successful in drawing conclusions on a small sample of respondents, including live-in migrant care workers (e.g. Chowdhury & Gutman, 2012 (14 in Canada) and Heng et al., 2019 (11 in Singapore)), or care receivers (e.g., Horn et al., 2019 (14 in Germany and 10 in the Netherlands)). Second, even though it was the authors' intention to give as much voice as possible to the older adults themselves, it was not always possible to interview them due to their cognitive or physical limitations. In these specific cases, close relatives (e.g. partner, children) were interviewed to obtain insights into their experiences. This has proved to be a useful strategy in similar studies (e.g. Horn et al., 2019). By the same reasoning, health professionals and staff members were interviewed. Although they were asked questions to research the care receivers' views, this might influence the data.

#### 6.4 | POINTS FOR DISCUSSION IN FUTURE RESEARCH

Despite these limitations, the paper provides new information and raises several points for discussion, to be addressed in future research. The first point raised is the availability of personcentred care. This study reveals that receiving more person-centred care motivates older adults to hire a live-in migrant care worker. As demonstrated in previous literature and in these results, this personcentred care cannot always be provided in the current formal care services, due to factors such as poor staff to care receiver ratios and high turnover rates (Horn et al., 2019). The demand to hire live-in migrant care workers also raises questions about the appropriateness of formal care services, as this research shows that these formal services are often either insufficient for older adults to be able to age in place or do not meet their needs. This is despite current policies wanting to support ageing in place, with a European-wide movement of 'de-institutionalisation' (Anttonen & Karsio, 2016) and Belgian governmental institutions setting up projects to achieve this (Smetcoren et al., 2018). Therefore, in examining the motivations to hire a live-in migrant care worker and older adults' preference for hiring Belgian caregivers, researchers could identify how formal care services could better answer care needs and wishes and improve the accessibility and usability of home care services for diverse types of older people (i.e. ageing in place, reducing informal carer workload and guaranteeing person-centred and continuous care).

Second, several questions were raised on the training, employment conditions and legal status of live-in migrant care workers. In Belgium, the relevant regulations are not clear. The International Labour Office states that 'Care recipients and care workers share a "common interest" in finding socially optimal care arrangements that maintain the quality of care, its suitability with the needs of workers with care responsibilities as well as respect for care workers' rights' (King-Dejardin, 2019). The precarious migrant status, isolation from organisational sources of support and lack of information for both parties contribute to poor working conditions and uncertainty about the quality

of care. Moreover, good quality care should be seen through the perspectives of both the care receiver and giver (Daly, 2001). While the perspective of the care receiver has dominated the discourse and political agenda on care provision (referring to established standards of care services, flexibility of the caregiver, adequacy of the care payment, etc), the perspective of the caregiver is hardly considered (referring to the opportunities for giving care, the relationships in which care is given, contractual arrangements and working conditions, etc.) (King-Dejardin, 2019). Just as in neighbouring countries (van Grafhorst, 2014), a gradual trend can be observed in the employment of live-in migrant care workers in Belgium, which necessitates further research.

# CHAPTER 4.

#### I AM PROUD BECAUSE I SUPPORT MY GIVE THEM CHILDREN AND A BF tfr FF: VF-IN NARRATIVES EXPLORING OF MIGRA CARE WORKERS THROUGH COL VIGNETTES

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#### CHAPTER 4. I AM PROUD BECAUSE I SUPPORT MY CHILDREN AND GIVE THEM A BETTER LIFE: EXPLORING NARRATIVES OF LIVE-IN MIGRANT CARE WORKERS THROUGH COLLECTIVE VIGNETTES

#### ABSTRACT

This paper explores live-in migrant carers' decisions to migrate and perform live-in care work for older persons in Belgium, personal and social changes stemming from their migration and care work, and the strategies they adopt to cope with difficult working and living conditions. Using a narrative approach underpinned by collective vignettes, stories from ten live-in migrant carers are collected through serial individual interviews (N=15). Results showed that fulfilling parental duties, escaping from an unsafe environment and seeking better mental health were motivations to migrate and perform live-in care work. Personal and social changes were experienced in migrants' transnational role as parent, partner and family member, and external and self-recognition. Coping strategies were found in feeling strong empathy for older persons, resigning themselves to their situation and seeking social support. The discussion critically reflects on the societal and political valuation of live-in migrant carers in relation to the research findings.

#### KEY WORDS

Transnational migrants, Transnational families, Care, Ageing, Global care chains

#### 1 I INTRODUCTION

Live-in migrant carers have been part of the care regimes of several European countries for decades already, such as Italy (Boccagni, 2018), Germany (Horn et al., 2019) and are emerging in others (The Netherlands (Da Roit & van Bochove, 2017), United Kingdom (Schwiter et al., 2018)). Depending on geography, cultural preferences, and policies on labour, migration and care, live-in migrant care work varies across countries in employment modalities (Ayalon, 2021; Horn et al., 2021; van Hooren, 2020), degree of formalization, carers' countries of origin and care arrangements (Eurofound, 2020). Although this type of care provision has only recently started to emerge in Belgium (Hoens & Smetcoren, 2021), and growing interest in and recognition of live-in migrant carers at the European (i.e. EESC, 2016; EESC, 2018) and Belgian policy level (Flemish Parliament, 2014, 2019) is observed, research in Belgium remains scarce and focuses mostly on migrant domestic workers in general (e.g. Giordano, 2017; Safuta, 2017), not on carers.

In response, this study aims to increase our understanding of live-in migrant care workers employed in Belgium. The dominant model to employ care workers in Belgium is through formal care organizations (Farvaque, 2013), therefore this context is an interesting addition to research in countries where care workers are primarily employed by families.

#### 2 | LITERATURE REVIEW

Although the literature often sees live-in migrant carers from a negative and passive perspective (e.g. referring to victimhood or abuse) (van Bochove & zur Kleinsmiede, 2020), live-in migrant care work is also described as a strategic choice and a deliberate decision (Ivanova, 2021; Schwiter et al., 2018), in order to achieve a higher social status or more favourable social conditions (access to educational opportunities, religious freedom) (Salami et al., 2014). In general, research most often concludes that it is mainly economic motivations which drive people to migrate (Urbańska, 2016): enjoying better employment opportunities (Bruquetas-Callejo, 2020; Da Roit & van Bochove, 2017) and providing financially for children (DePalma et al., 2021; Salami et al., 2014) are common motivations. Through transnational mobility, personal life projects can be enabled (Eurofound, 2020). Transnationalism conceptualizes migration as a dynamic, ongoing process that requires work and maintenance of relationships (Glick Schiller et al., 1992), rather than a state. Through migration, people undergo personal and social changes and transnational lives become a mixture of places, networks, identities and relationships (Ivanova, 2021).

An important factor in the experience or quality of these transnational lives is the work migrants perform. Several studies reveal the hard working conditions of live-in migrant carers, such as long working days, low pay and no social security for irregular work (Bruquetas-Callejo, 2020; van Hooren, 2012). One way to cope with such difficult working and living conditions is looking for social support. Van Bochove and zur Kleinsmiede (2021) have shown the importance of other care actors (client-related and non-client-related) in shaping the experience of precarious work. While some live-in migrant carers have access to well-functioning client-related relationships, where relatives or formal caregivers are substituting for the live-in carer and allowing them to have some time off, not all live-in migrant carers receive emotional or practical support from relatives of the care recipient (van Bochove & zur Kleinsmiede, 2021). Literature warns that while close informal relationships between employers and live-in carers can be a social protection strategy (Safuta & Camargo, 2019), they might

also lead to emotional exhaustion and risks of exploitation (van Bochove & zur Kleinsmiede, 2020) because of the unequal distribution of power and control. While a live-in carer can be seen as part of the family, in most cases a hierarchy remains (Hoens & Smetcoren, 2021). Boundaries between professional and personal relationships and between work and leisure are often unclear (Safuta & Camargo, 2019; van Bochove & zur Kleinsmiede, 2020). Safuta (2017, p.312) referred to this as personalization, by which *"individuals do not know anymore whether they provide emotional work because they are expected to do so as part of their occupational role of domestic workers [...], or because they want to, as part of any individual's private emotional work"*. Long working days and a lack of adequate rest may be the result (Heng et al., 2019). In addition, social relationships outside of the client-related actors are vital to cope with especially emotionally challenging elements of the work. Those who work longer in the host country can build a support network near their workplace. Regular transnational contacts with family and friends in the country of origin are also an important source of support (van Bochove & zur Kleinsmiede, 2021), since reconnecting with family may relieve psychological stressors such as loneliness or family concerns (de la Cuesta-Benjumea et al., 2011).

#### 3 | RESEARCH QUESTIONS

In investigating the personal and social changes live-in migrant carers go through, this study acknowledges the dynamic aspect of migration and transnational lives. This study likewise aims to increase our understanding of the role of social support networks in coping with the challenges of live-in migrant care work, while paying attention to asymmetrical power relations and transnational care. In doing so, the article adopts a narrative approach underpinned by collective vignettes. Narrative research offers embodied presentations of life, demonstrating how individuals act in their social worlds (O'Shea, 2015). It captures the complexity of situations in which actions are undertaken and the attached emotions and motivations (Polkinghorne, 1988). By using collective vignettes, the data are presented in a coherent and meaningful way, including the voices of multiple storytellers (Richardson, 1988). The following research questions are addressed:

- 1. How do live-in migrant carers in Belgium explain their decision to migrate and perform livein migrant care work?
- 2. How do live-in migrant carers experience and deal with the personal and social changes resulting from migration and work as live-in carers?
- 3. How do live-in migrant carers make sense of and cope with their working and living conditions?

#### 4 | METHODS

In this qualitative study, findings are reported in the form of collective vignettes. The study uses the Consolidated criteria for Reporting Qualitative Research (COREQ) to report on the methods of this study design (Tong et al., 2007).

#### 4.1 | DATA COLLECTION

Qualitative interviews were conducted with live-in migrant carers in Belgium. Each participant was interviewed at least once. Online serial interviews (Read, 2018) were conducted with those

participants who were willing to be interviewed more than once. In total 15 interviews were conducted, with 10 respondents. Through serial interviews participants were interviewed on multiple occasions, meaning five participants participated in a second interview. This fosters familiarity and trust in which participants feel more comfortable to share experiences. Additionally, key topics are probed more than once and more in-depth information can be gathered (Read, 2018). Some interview sessions were affected by participants' time constraints due to their working hours and on-call duties, and therefore benefitted from an extra session.

The data were collected between November 2020 and March 2021. Because of social restrictions imposed in light of the coronavirus pandemic, 14 interviews were conducted online (via WhatsApp Videocall, Facebook Messenger Videocall, Skype or Whereby, depending on the participant's preferred platform). One interview was conducted by email, because the participant felt uncomfortable with an online or face-to-face interview. This was an asynchronous interview in which the participant received an email with questions and could reply at her convenience (Gibson, 2017). The first author conducted the interviews, together with an MSc student trained in qualitative research methodology and the research topic. The interviews lasted between 25 and 68 minutes, with a mean of 46 minutes. Data saturation point was reached because of the richness of the data, meaning that additional data did not lead to new emerging themes as it tended to reinforce the previous findings (Saunders et al., 2018). The interviews were conducted in French, English or Spanish, depending on the language spoken by the participant. Both interviews were audio recorded and transcribed verbatim.

During the first interview, questions were asked on the following topics: (a) motivations to do live-in migrant care work; (b) experiences of the live-in migrant carers; (c) perspectives for the future of the live-in migrant carers. The second interview started with member check questions: analyses of single participants' data of the first interview were discussed to obtain feedback from participants and add validity to the researchers' interpretations (Birt et al., 2016). The interview further focused indepth on the experiences of the live-in migrant carers, and included the following topics: (a) work as live-in carer; (b) well-being; (c) relation with care recipient; (d) social network; (e) support.

#### 4.2 | PARTICIPANTS

The criteria for inclusion of participants were: adults who were providing live-in care in Belgium for a person over the age of 60 (at the time of the interview or in the recent past), and being a first-generation migrant. Participants (N=10) were recruited through different channels. Several key figures of ethnic minority organizations (clergy of foreign-language services, community representatives) were first contacted and asked whether the researchers could come visit to explain the research and ask potential respondents to participate. Despite the visits, this recruitment strategy did not generate participants. Various agencies offering live-in care services in Belgium were simultaneously contacted to invite live-in carers to participate in the study. Only one agency responded positively and invited live-in carers to participate, resulting in one participant. Another participant was recruited through an NGO the researchers were already in contact with, which offered legal support to migrant domestic and care workers in precarious situations. The other participants were recruited through personal contacts (acquaintances, home nurses in the researchers' personal network) (N=4) and Facebook groups on live-in care (N=4). Snowball sampling did not yield any participants.

An overview of the participants' characteristics can be found in Table 4. The majority of participants were female (N=8) and came from Romania (N=6). Others were from Guatemala (N=2), the Philippines (N=1) and Sri Lanka (N=1). Most participants worked in Belgium with a regular residence status. Their mean age was 52 years (range 38 to 67). Six participants had previous experience with care (formal or informal) and four participants had followed a short nursing course in their home country. Five participants were formally contracted by an employment agency, the others did not have a contract. Participants from Romania commuted between Belgium and Romania, meaning they would take their holidays regularly in Romania. The profiles of the older men and women they were taking care of were diverse. They lived geographically spread over Belgium, and the majority of the older adults was highly dependent on care due to their health condition (e.g. dementia, Parkinson's, cerebrovascular accident).

| Characteristics                                |             | Interview 1<br>(N) | Interview 2<br>(N) |
|--|-------------|--------------------|--------------------|
| Gender   | Female      | 8                  | 5                  |
|  | Male        | 2                  | 0                  |
| Age (years)                                    | 31-40       | 1                  | 0                  |
|  | 41-50       | 3                  | 1                  |
|  | 51-60       | 4                  | 4                  |
|  | 61-70       | 2                  | 0                  |
| Country of origin                              | Romania     | 6                  | 3                  |
|  | Guatemala   | 2                  | 1                  |
|  | Philippines | 1                  | 1                  |
|  | Sri Lanka   | 1                  | 0                  |
| Marital status                                 | Cohabiting  | 1                  | 0                  |
|  | Married     | 6                  | 3                  |
|  | Divorced    | 3                  | 2                  |
| Prior caregiving experience (formal/informal)  | Yes         | 6                  | 3                  |
|  | No          | 4                  | 2                  |
| Short nursing course in home country           | Yes         | 4                  | 3                  |
|  | No          | 6                  | 2                  |
| Working with a written contract of employment  | Yes         | 5                  | 3                  |
|  | No          | 5                  | 2                  |
| Total live-in caregiving experience in Belgium | <1          | 1                  | 0                  |
| (years)  | 1-5         | 4                  | 2                  |
|  | 6-10        | 2                  | 2                  |
|  | >10         | 3                  | 1                  |

#### TABLE 4 Participants' characteristics

#### 4.3 | DATA ANALYSIS

Collective vignettes are used to present the data in a coherent and meaningful way, including the voices of multiple storytellers (Richardson, 1988). To develop these vignettes, the data were analysed using a combination of the analysis strategies of Blodgett et al. (2011) on individual vignettes, Paquette et al. (2019) on composite vignettes, and O'Shea (2015) on collective vignettes. Collective vignettes entail multiple storytellers, recognizing the social bondedness between the participants and

moving away from the isolated narrator (O'Shea, 2015; Richardson, 1988). To acknowledge the unique biographies of the participants while at the same time recognizing the commonalities of their experiences, we deliberately choose to identify each quote by its speaker, rather than present multiple voices as one narrator (e.g. composite vignette). The collective vignettes give unity and meaning to data, inviting readers into the lived experiences of the participants (O'Shea, 2015).

Prior to starting the coding process, the transcripts were read multiple times by the first author and discussed with the co-authors, whereafter initial thoughts were noted. During the coding process a line-by-line inductive analysis of the transcripts was conducted. Coded data were then organized into starting themes (e.g. motivation, positive and negative experiences, ways of coping) based on participants' experiences. At this stage of the analysis, the different profiles of the participants became clear. Through consolidation and refinement of the starting themes, the finalized themes (e.g. offering children a better future, deeply felt repercussions, redefining role of motherhood, economic role) were created with a focus on capturing the broader narrative and experiences of the different profiles. These finalized themes were the guiding framework for the development of the collective vignettes (e.g. the path to fulfilling parental duties), as they formed the 'narrative skeleton' of the vignettes.

To preserve the active voice and authenticity of participants and their experiences, direct quotes from the interview transcripts were maintained as much as possible. The experiences of the participants contained in the narrative skeleton were then linked together by connecting sentences. In this way, full and fluent representations of the participants' stories were developed as collective vignettes.

#### 4.4 | ETHICAL CONSIDERATIONS

The study was conducted in conformity with the guidelines of the Human Sciences Ethical Committee of Vrije Universiteit Brussel (VUB) and the European Framework for Research Ethics (European Commission Directorate-General for Research and Innovation, 2012). The research process, with any possibly associated harm and discomfort, was reflected upon by a team of researchers. The details of the study were set out in an informed consent document and were also explained orally to participants prior to the interview, including the broader objectives, the right to withdraw at any time, data governance and information on confidentiality. All participants gave both written and verbal consent for an audio-recorded interview. Any identifying information was removed (e.g. participants' real names and places), and pseudonyms were used in the Findings section.

#### 5 | FINDINGS

The findings present the diverse experiences of live-in migrant carers through collective vignettes. The research questions will be answered throughout the different themes of the vignettes. The vignettes discuss parental duties, external and self-recognition, social support, and ways of coping with working and living conditions.

#### 5.1 | VIGNETTE 1: THE PATH TO FULFILLING PARENTAL DUTIES

The decision to migrate and perform live-in migrant care work was motivated by different needs. For the majority of participants it was driven by an urge for economic betterment, others wanted to escape an unsafe environment (e.g. crime) or improve their mental health. It was often an active choice in the pursuit of a higher goal, such as saving money to buy a house or **offering their children a better future.** This last motivation was echoed in multiple stories of live-in migrant carers. Dinesh (45) migrated from Sri Lanka to Italy when he was 16 and recently lost his job in a supermarket there. Acquaintances knew someone in Belgium who could employ him as live-in carer, so he moved to Belgium four months ago "to earn money to pay for my son's studies". He saw his migration to Belgium as something temporary to earn and save money in order to be able to move back to Sri Lanka and open a hotel. His purpose was not to develop a care career in Belgium, he had rather envisioned returning home with money in-hand to secure a material future for his son and himself.

Similar reasoning was described by Aura (63) from Romania. When her country joined the European Union 14 years ago and working within the European Union became possible for her, she started working as a live-in carer in different European countries, including France and Switzerland. Over the last few years she had been commuting between Belgium and Romania. Her motivation was to take care of her adult children, "to give my children happiness. Because I have a boy who is 32 years old and he is now a gymnastics teacher. And I have a daughter who finished university for nursing." She then quickly adds that this motivation alone would not be sufficient to continue performing the job: "I like to help older people. Doing this job is very difficult. You need to have a warm heart for it." Aura was the only one of her family living in Belgium, where she works for about seven months at a time and then takes brief holidays in Romania. She describes her feelings: "It's very difficult to be away from my family. Now I am already a grandmother of two little boys. It's very difficult. But life is life. When you have to work, that's what you need to do. But family is very important. Family always sticks together and so I can do the job away from my family, because they will always be next to me."

While Dinesh and Aura intended to work temporarily in Belgium, other participants indicated that **they saw their future and that of their children in Belgium**. Jonalyn (53) migrated 11 years ago from the Philippines to Belgium. Her four children stayed in the Philippines and were between 5 and 16 years old when she left. She has not had the chance to meet them physically since she left 11 years ago. Jonalyn: "Work is very limited in the Philippines and the salary is very low, so it was not good enough to support my four children. I had to go outside the country to look for another place to work. Fortunately, I came to Belgium and I can stay here. I like Belgium for work but for enjoying my life it's a little bit complicated because I'm staying here only to work, work, work." Looking for a job abroad was a common strategy in the Philippines: "Most Filipinos are striving to get out of the country, leaving their family, leaving everything behind, just to have a chance to support their families in the Philippines." Jonalyn further explains: "My greatest dream is to reunite with my children, that they can come here and work, so they can support their own family, like me." She adds that they could also work as live-in carers: "When they were young, I would dream that they came here. Because then they could go to school, have a better education and have a good job. But now, I don't know what kind of work they can have. But I hope they can have the same job as me."

While the motivation for those parents was to ensure a better future for their children, the decision to move abroad had **deeply felt repercussions**. They **have not seen their children** for a long time, which comes at a high emotional cost. Carolina (46) from Guatemala left her country very suddenly eight years ago and only realized in Belgium that she had actually left her children for a long time: "I was afraid to go out, I had lost confidence, the violence was strong in our country, so I was afraid to go to work. And I was afraid because I had three daughters to take care of. So I talked to my parents and they told me 'Daughter, as long as we are alive you have our help'. And I told them 'I want to go, I want to go to work. My brother [who was already in Belgium] told me that it's nice, that you can work and that you can be free. And

I decided that I will go.' But I didn't fully realize that I was going to leave my daughters. And everything happened so fast that I didn't realize it, until I was here, that I had left my daughters." Carolina explains further: "I have my parents who take care of my children. When I realized that I had left my daughters it was hard, but I didn't do it for something bad, but for something good. It was a very high price to pay, but every mother I think would do it." Migrants' identity and parenting roles were redefined, as they had to deal with spatial separation and maintaining contact mostly through their phones and the internet. Jonalyn talks about how she adapted and created novel ways of transnational parenting: "Before it was really difficult, but now that we have internet it's easier because I can hear them and see them all the time. It's like I'm with them. So I make sure that before they start their day, I send a message every day. I never fail to send a message to each of my four children: 'You should do that, you shouldn't do that', until they grow up, until now. Sometimes they would say 'Mama we already know what you're going to say'. So it's not so hard anymore like before, because now I can hear them and see them all the time." Carolina explains a similar way of coping with physical distance thanks to the use of technology: "I talk to my daughters every day on WhatsApp. We do videocalls and everything. My daughters know me. They don't know me physically, but they know me on the phone. I can't give them a hug, I can't give them anything like that. I can't touch them or anything, but I follow them, I follow them every day —whether they have homework, how they're doing at school. I'm in contact with them. It's not the same as if I could see them, but I know them. I've seen their changes on the phone, every stage they've gone through. Five years ago, I cried a lot, but then I said 'What's the use of crying, it's not worth it, I have to accept the decision I made, to come here'. You have to look ahead and see if it's worth it. And I feel proud of what I do for my daughters." Hence these live-in migrant carers are facing a paradoxical situation: strong family bonds and securing a better future for their children results in leaving them behind, often lacking physical interaction for a long time.

Cristina (58), a divorced Romanian mother of two adult children and four grandchildren who first started working in Belgium 11 years ago, tells that working as a live-in carer is okay for her because "I was able to help my children during a difficult time. It was a time when I didn't have a job and I needed to send money to my country". This experience emphasized her economic role as a mother. Carolina adds that as a single mother, she is the only source of financial support for her children at home: "I don't have the luxury of being out of work because I need to earn every month, because I have three daughters who are studying. I would like to study, but who is going to support my daughters? My daughters depend on me. It is a luxury that I cannot afford." In all their narratives, the role of the partner was barely mentioned. This finding will be addressed in the Discussion.

#### 5.2 | VIGNETTE 2: THE PATH TO EXTERNAL AND SELF-RECOGNITION

For some participants, working as a live-in carer in Belgium entailed a process of finding themselves and feeling recognized for their work. For Carolina, migration made her a **stronger person** after divorcing from her partner: "When I was with my partner, I had lost my self-confidence, I didn't recognize myself. And here I found my confidence again. I am the same again as when I was little. Belgium has given me strength, I found my strength."

Jonalyn struggled in the beginning with the **negative connotations** attached to live-in care and for a long time kept her work hidden from her family. She felt it was a secret that could not be shared out of fear of negative reactions. Her fear of these reactions seemed related to downward occupational mobility. In the Philippines she employed a cleaning lady in her house and was now afraid of her fellow countrymen's reaction: *"They would say 'You are a professional in the Philippines and now you're*  cleaning a house yourself? In your own house here, you have a cleaning lady and now you are doing it yourself.' So that discouraged me. So I never told them. Most of the Filipinos don't tell in the Philippines how we work here." Jonalyn further clarified that her fear and shame were the result of the overly positive aspirations that many Filipinos have with migrating and jobs in the host country. Therefore, before migrating herself she never considered the possibility of working in domestic care services: "I didn't imagine myself working like this, but we Filipinos, we don't have any options. My friend is an engineer, another friend is a teacher, but they are doing the same jobs as me because we don't have other opportunities. In the Philippines they didn't tell me. I looked up to them, I never imagined that they worked like this. They portray their life in Belgium as great, they never tell us what kind of work they really do. So when I arrived here in Belgium I couldn't accept that this is the life I would have and the work that I would have to do." However, after a while she began to feel proud of her work when she realized that her money could support her children: "Now I am proud to do this because this is the way I support my children and give them a better life (...). Because of the love of the family, the work that we didn't like before, we value now." She adds that her children recognize her work and appreciate what she is doing for them: "I realized that I wanted my children to value the money I send them, it's the fruit of my labour, it's my sweat and blood. I'm so happy that my children, as they grow up, give importance to what I'm doing and value the money I send them and spend it in a very good way." Jonalyn now even makes videos showing her work to share with friends in the Philippines: "This is my way of thinking now, I'm not ashamed to tell anyone. In the Philippines, I tell them we don't have any choice, this is the job that we have to do. [...] And now, they are more proud of me, because I'm not ashamed to tell them. And they don't look at me as a domestic worker, they look at me as a person." Cristina also emphasizes the importance of recognition from her family: "My children respect my work a lot. They can't believe it that I could endure it for so long, they admire me."

Additionally, the recognition of the family of the older person they care for could help in this process of self-recognition. Jonalyn: "My employer treats me like their own family. They love me and I love them, so it's rewarding." Andreea (41), an experienced live-in carer from Romania who has been commuting between the two countries for 14 years: "It gives me satisfaction when I see that everything is all right. I like in my job that I can feel the gratitude and love of the family. It gives me joy if I can help. In one case, the older woman's son thanked me that I made his mother's last years happy."

#### 5.3 | VIGNETTE 3: THE PATH TO SOCIAL SUPPORT

While some live-in migrant carers came to Belgium because they already knew some people, others did not know anyone before their arrival. To Dinesh, investing in building a social network is not self-evident: "It's difficult because my whole family is in Milan and I don't know anybody here. There is nobody here from my country, some people from India, but nobody from Sri Lanka. So it is difficult but I plough on. It isn't easy to get to know people, because I work here and I'm in this house 24 hours a day, so I don't go anywhere." He felt his sense of belonging was linked to his national identity; since he did not have contact with people from Sri Lanka in Belgium, Dinesh was not satisfied with his social network and did not feel comfortable there. His **relationship with the older person** he took care of became very important to him: "He is a quiet person, I like that. He smiles a lot, he talks, he jokes. If it wasn't for that, I would have gone back to Milan already. Not because it's difficult. Difficult work does not exist for me, work is work. But it is mentally hard, because my son is not here, I have no friends here."

A feeling of homesickness for both the home country and the family left behind was outlined in multiple narratives. Florina (67), who retired in Romania and commuted between her country and

her job in Belgium as live-in carer, describes her feelings: "It's good here in Belgium, but at home it's better.[...] But on the other hand, here I feel at home too, because I got used to it very quickly." Daniela (53), who started commuting between Belgium and Romania eight years ago, explains how she missed her family, but that her bond with the older person substitutes partly for this feeling: "I miss my family. I am a person who normally hugs a lot, I miss that. But for example in the evening when I put madam in her bed gently, I talk to her. She's happy when I talk to her softly and this also helps me."

While the job is physically and emotionally demanding, social support often helps live-in carers cope. Migrant carers used different strategies to look for social support. Some maintained strong contacts with family in their home country. Izabela (57), who started working as live-in carer five years ago, commutes between Romania and Belgium. At the moment of the interview she was on sick leave, which she spends in Belgium for doctor's visits. Izabella: "I talk with someone from my family every day. Sometimes my daughters come visit me. My daughters help me with all my problems. They ask me 'Do you need something? You just have to call." Dinesh adds: "Every half hour, every hour, I have contact with my family through WhatsApp. If we have time we videocall. If it has to be quick, we chat." Some participants also mentioned the **feelings of family who stayed behind**. Daniela points out that it was difficult for her partner to be separated: "I'm happy with my husband, I talk to my husband every day, we both trust each other. But it's hard to live like this, like us. For my husband it is difficult to cook alone, to live alone. But every day we talk, so I'm happy." Javier (38) migrated from Guatemala with the intention of staying for a longer time in Belgium. The first years after his arrival he was working as a live-in carer, now he is expecting his second child with his girlfriend who he later met in Belgium. He describes the feelings of his parents, while also explaining that it was difficult without their support: "They were sad because when you emigrate from this country, you know that it will take you at least five or six years to return. It is also difficult to leave your parents for a long time. Here you learn to live alone."

Another strategy to look for social support were solidarity bonds between migrant workers who shared similar experiences. The live-in carers from Romania were **seeking contact with other Romanian workers in Belgium**, as Izabela explains: "I got to know the other people who work for the agency and we started talking on Facebook. Later we would meet during our day off. We often go for a walk. Together with the family you decide when you take your day off, so some people cannot join because their family doesn't understand it."

#### 5.4 | VIGNETTE 4: THE PATH TO COPING WITH THE WORKING AND LIVING CONDITIONS

Participants frequently combined narratives of coping with difficult working and living conditions with accepting them and making the best out of it. Doing live-in care is often a strategic choice in the pursuit of economic independence and stability for their children, which often makes hard working conditions bearable.

Several participants experienced the work as **emotionally draining**, because they got attached to the older person and sometimes took care of them during their last days. In the words of Javier: "It was a very enriching experience, very pleasant above all. But also very sad, because when you do a job, you are with a person for two or three years and then you have to say goodbye. So people who do this kind of work are brave, more than anything else. Because they live with different people all the time. It's good and it's bad. Because you know the person you take care of and you know that he or she will very soon leave."

Many of the interviewed live-in carers experienced this type of work as **physically exhausting**. Andreea tells: "It takes a lot of energy to take care of somebody who cannot do anything on their own. It is difficult to do everything. The good part is that I have some special equipment which makes the job somewhat easier. I have for example a patient lift, which makes moving the person in and out of bed much easier." Daniela adds that the long working days made it tiring as well, especially because she had to follow the rhythm of the older person: "Madam had a cough last week. She coughs all night long and it's very tiring for her. And for me it's tiring because I'm not able to do as I want. I'm tired when I don't sleep at night. The doctor told me that I'm very tired and I cannot work like this all my life. Staying like this, tired, tired, it's not good for me." She did not have fixed hours and was available at all times: "My life is all the time here, 24 hours per day, I don't have freedom. I can't go out to the garden because madam is dependent on me. So I'm always in a hurry, always quickly, quickly, to stay close to her. I'm always listening whether she doesn't need me, I cannot say that I'm free. So I don't really have [limited] working hours." In Cristina's words: "You have to stay almost all the time by their side. And sometimes you don't get to rest at noon like you have the right to. It depends on the day and it's not the person's fault. There are working hours, but a sick person doesn't understand that." Her strong empathy for the person's situation made her accept long working hours.

The extensive and unregulated working hours in live-in care impact workers' free time. Daniela says it isn't easy to meet with people because of time constraints: "Normally [as stipulated in the contract] on my day off I'm free from eight in the morning until eight in the evening. Another person then comes to replace me until four PM. But as I live in a small village here, I have to take the bus for more than an hour when I want to go somewhere. So I have to return in time and be back by four. I have accepted it." Other live-in carers working with a contract also complain about free days being shorter than agreed upon in the contract. Additionally, Javier tells he had to follow the schedule of the older person for his leisure time and this **impacted his social interactions**: "Normally I used to hang out with people, but I couldn't go for a beer with a friend anymore because I was working. I had free time, but I couldn't leave the house, I had to be on standby. Because she is a person who needed help with walking. She needed help getting around, she needed help to go to the garden because at night she wanted to see the moon, so I helped her. She had a schedule, so I had to follow."

Asymmetrical power relations between live-in carers and older people and their family were expressed in multiple narratives. For instance, Carolina describes how the children of the older person unilaterally decided on her working hours: "In the beginning I would work from Monday to Saturday. If I stayed during the weekend, they [the children] would pay me extra. But when the person became very sick they wanted me to stay the whole week. They wouldn't let me go out. They paid me extra, it's true, but I didn't want money. I wanted freedom. I couldn't stay there for 30 days on a row. I needed to breathe and go out. They were good to their mother, but I needed to take care of her 100%. And I told them that I needed to go out on weekends to recharge, to come back with new strength. It made it physically and emotionally hard for me. In the last months, the children were also tired and only visited on weekends."

These power relations negatively impact migrants' working conditions and makes them particularly **vulnerable to employers' demands**, even more when precarious contracts limit the power of live-in migrant carers to negotiate their working conditions. More specifically, live-in migrant carers who did not have the appropriate documents to work in Belgium were forced to remain at the margins of society and could not access social security benefits. Jonalyn, who lost her job in-between her two interviews, on how this went: "I'm so sad to tell you that I lost my job. So I am looking for another job now. And it's just because of my situation, just because I don't have papers they can easily remove me from the job any time they want. I like to tell you that it's my employer's intermediary [e.g. family member/friend who arranges the practicalities] who decided to take me out of the job. There are so many problems arising with the intermediaries. All of the old people that I have worked with, they have intermediaries and they're the ones who

manipulate everything. I don't have any problem with the employer but with the intermediaries, if I cannot please them, then I will regret it." The lack of a contract contributed to Jonalyn's difficult situation: "Most of the employers do not want a contract. That's why we don't have a choice and we endure this hard work. I would like to have a contract but when I ask my employers they refuse. Because they know they will violate the contract and they want to take advantage of us. In a contract they would not be able to put all the things they ask from us like 'you have to work more than eight hours' and there are a lot of problems with the payments [e.g. late payment, not paying all the working hours]."

Nevertheless, Jonalyn showed that she still exercised resistance, within the limits of what her situation allows, to overcome these daily oppressions: she filed a complaint against an abusive employer with the help of an NGO specialized in legal support to migrant domestic workers. However, during the interviews most live-in carers often expressed feelings of resignation with the situation. For instance, Carolina is grateful to the daughters of the older person replacing her so she could have time off: "When I started working with them, the children realized that I wanted to learn the local language. So one of the daughters would replace me on Tuesday and Thursday mornings so that I could take French classes. So they helped me, two half-days, one daughter said 'We are going to help you so you can learn and you can communicate better with my mother'. (...) And thank God she wanted to help me and she said 'I will replace you, when you go to school I stay with my mom'. She helped me a lot during the two years I worked with them and she allowed me to go to school to study French so I could get along better with her mother." While in her narrative Carolina expresses gratitude towards the family and praises their generosity, the quote also indicates that the responsibilities for the care and wellbeing of the mother had been nearly completely displaced from the children to Carolina. The justification for 'allowing' Carolina to leave the mother's side is not her own empowerment, it served to improve communication with their mother.

#### 6 | DISCUSSION

This study used a narrative approach to explore live-in migrant carers' decisions to migrate and perform live-in care work, personal and social changes stemming from migration and care, and the strategies they adopt to cope with difficult working and living conditions.

In response to the first research question, some participants were motivated to migrate in order to escape from an unsafe environment (tense family relationships, domestic violence (Goździak, 2016; Urbańska, 2016)) and seek better mental health. Yet most often participants explained their decision to migrate and perform live-in care by the need to fulfil parental duties. They wanted to offer their children a better future, even if this came with deeply felt repercussions, like separation. This focus on 'all for the family' in participants' narratives is also expressed by Salami et al. (2014) in a study of Filipino nurses in Canada. The authors describe their willingness to (at least temporarily) sacrifice and tolerate hard working conditions in order to improve the future of their children. However, after migrating the live-in migrant carers participating in this study had to redefine their roles as parents.

When exploring the second research question, how live-in migrant carers dealt with personal and social changes, it became apparent that dealing with spatial separation from their children results in transnational (child) care circulation (Baldassar & Merla, 2014). Because migrant carers feel responsible for the children left behind, they keep close relations with family and friends in their home country. This transnational context urges them to redefine their role as parents. The literature discusses innovative mothering strategies: hands-on, physical, practical, emotional, financial, material,

housing (Merla et al., 2020). Baldassar and Merla (2014) define this as transnational care circulation, taking into account the broader socio-structural context in which families operate transnationally. In our study caring for their children mainly took on a different form, in which financial contributions replaced physical presence. DePalma et al. (2021, p. 1) describe this process as "actively reinventing motherhood by (re)constructing financial contribution as a type of caring".

A second change concerns the path to external and self-recognition: similar to their social network and the wider society, live-in carers originally attached negative connotations to performing live-in care such as downward occupational mobility or overly positive aspirations of employment opportunities in the host country. However, the realization after a while that they were actively supporting and contributing to their family, and the recognition of their family and the family of the older person helped them grow in self-recognition and feeling pride in their work. These narratives confirmed the previously formulated global struggles with recognition of domestic work as decent work and undervaluation of care (which is often not perceived as work), and the role social support could play (Peterson, 2018).

In addressing the third research question, participants indicated that live-in care was emotionally and physically hard work. Long and undefined working hours negatively impact possibilities for free time and social interaction. Declining tasks or setting boundaries is difficult due to asymmetrical power relations mainly resulting from lacking or precarious contracts. Respondents identified three main strategies to cope with these precarious working and living conditions. First, several live-in carers mentioned the strong empathy they felt for the older person. Nonetheless, as previously pointed out by Safuta (2017), this type of emotional investment can make it even more difficult for workers to quit or set boundaries at work. Second, several live-in carers used a more emotion-focused or passive coping style (coping strategies related to avoidance of emotion or cognitive regulation) and expressed feelings of resignation with their situation, although working conditions can be experienced as bearable as long as employment facilitates long-term personal goals (Bruquetas-Callejo (2020). Third, seeking social support was often mentioned as a key coping strategy. Maintaining strong contacts with the family at home or with other workers in Belgium in a similar situation was a key source of support. However, investing in building a social network was not easy because of the limited free time. This explains why, for some live-in migrant carers, the relationship with the older person becomes essential. While literature also highlights the role of client-related care actors (van Bochove & zur Kleinsmiede, 2020), participants very rarely received support from them, for example to enable the workers to have some time off. Instead, the live-in migrant carers are often the only real caretakers and care receivers' children leave the responsibility with them.

The collective vignettes show a strong approach to depict participants' lived experiences in their own words. In that way, participants are seen as the experts of their own realities and readers gain deeper understanding of their experiences (Blodgett et al., 2011). Nevertheless, the findings in this study are subject to at least two limitations. First, the use of online interviews, due to social distancing recommendations related to the coronavirus pandemic, made it challenging to establish a trusting relationship and obtain in-depth information, as also experienced by Dos Santos (2020). Conversely, due to participants' limited free time, online interviews offered a convenient way to meet (Janghorban et al., 2014). Second, as demonstrated by Safuta (2016) and Urbańska (2016), we could argue that participants' answers could have been influenced by social desirability concerns and should therefore be interpreted in a wider context. The method of 'asking the materialist question', where attention is paid to what is absent in participants' narratives (Safuta, 2016), could possibly reveal why participants

barely mentioned their partners' role in childrearing. Although interviewers did not specifically ask about partners, their absence in participants' narratives is puzzling. This omission might be attributed to traditional gender roles regarding care or explained by the fact that some migration was motivated by domestic violence (Urbańska, 2016). Future research could therefore consider the role in the transnational lives of live-in carers of partners who stayed behind.

Building on the findings of this study, some recommendations for policy and practice can be made. There is a need for increased societal and political valuation of live-in migrant carers. Their precarious living (e.g. not being able to travel back home and see their children for 10 years) and working conditions (e.g. expectation of working round-the-clock, with no or limited time off) arise from asymmetrical power relations on a global (e.g. being forced to migrate for economic reasons) and local level (e.g. between older adults, the family and live-in migrant care workers), where individual live-in migrant care workers have little bargaining power. Therefore live-in migrant carers should receive political valuation, as political regulations shape the working and living conditions. A formal employment status can reduce precariousness and enhance opportunities for reporting labour rights violations (Fisher, 2021).

## CHAPTER 5. CAPTURING THE MOST SIGNIFICANT CHANGE AFTER A WORK-TRAINING PROGRAM FOR COMMUNITY HEALTH WORKERS

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## CHAPTER 5. CAPTURING THE MOST SIGNIFICANT CHANGE AFTER A WORK-TRAINING PROGRAM FOR COMMUNITY HEALTH WORKERS

#### ABSTRACT

This paper examines the changes community health workers experienced after following a ninemonth work-training program and the enabling/disabling factors leading to these changes. Using the Most Significant Change technique, stories from community health workers were collected through individual interviews (N=9) and discussed in a focus group (N=7). Results showed that increased knowledge, social skills and attitudes, facilitated employability, enlarged social networks, and gained social recognition were highlighted as Most Significant Changes. Mentoring, peer learning and peer support, and experience-based learning were indispensable in realizing those changes. Stories were selected as significant when they were recognizable, inspirable, or admirable.

#### KEY WORDS

Most Significant Change, Community health workers, Work-training program, Mentoring

# 1 I INTRODUCTION

In Brussels (Belgium), the number of older adults aged 65 and older with a migration background increased from 28.0% in 2011 to 40.9% in 2021 among the general older population (StatBel, 2021). Professional home care providers face barriers in reaching this population (Suurmond et al., 2016). On the one hand, barriers can be detected at the individual level of older adults with a migration background, such as language barriers, lack of familiarity with the healthcare system, lack of social networks that facilitate access to timely care, and insecurities related to intercultural encounters with care professionals (Ahaddour et al., 2016; Kristiansen et al., 2016). On the other hand, barriers relate to the inadequacy of care organizations in addressing the needs of older adults with a migration background. Examples are one-size-fits-all approaches and a lack of cultural competence of the care professionals (Berdai Chaouni & De Donder, 2019). The latter is demonstrated by care professionals' narrow perceptions of "homogeneous problematic groups with special needs", their insecurity and fear of handling incorrectly, and *othering* (micro-racism by defining "the other") practices (Claeys et al., 2020). A possible solution for care organizations to reach older people with a migration background is to collaborate with community health workers who have a migration background (Delgado, 2020). Community health workers "serve as a link between patients and health care providers in order to reduce health care disparities" (Shommu et al., 2016, p. 2). This study aimed to examine the impact and process of a nine-month work-training program for community health workers in Brussels, using the Most Significant Change technique. This technique allows gathering changes that are personally valued by the trainees (Choy & Lidstone, 2013).

# 1.1 | WHAT ARE COMMUNITY HEALTH WORKERS?

Different terms are used to describe community health workers, such as health coach, health educator, outreach worker, liaison, or health promoter, identifying various roles and responsibilities (Delgado, 2020; O'Brien et al., 2009). Regardless of the terminology used, the primary goal of community health workers is always to reach those people most in need of care and groups that are hard-to-reach by general care services (Delgado, 2020). A comprehensive definition is provided by the American Public Health Association (2020): "Community health workers are frontline public health workers who are trusted members of and/or have an unusually close understanding of the community served. This trusting relationship enables community health workers to serve as a liaison/link/intermediary between health/social services and the community health workers are a relatively new profession of frontline public workers, compared to social workers, who have a long history of working in communities by providing behavioral health, case management and advocacy services (Berrett-Abebe et al., 2020). In contrast to social workers, community health workers are often members of the community they serve (Spencer et al., 2010).

Benefits of working with community health workers can be seen at the level of care recipients: trust-building with care recipients via home visits (Malcarney et al., 2017), patient and community empowerment regarding health (Delgado, 2020; Malcarney et al., 2017), and connecting people to broader services (such as transport and housing) because of their focus on social determinants of health (Malcarney et al., 2017). On a personal level, community health workers feel a personal responsibility to disseminate knowledge, promote healthy behaviors in their community, and improve

health services (Ludwick et al., 2014; Schurer et al., 2020). By improving health services, community health workers feel proud to contribute to the community (Ngilangwa & Mgomella, 2018; Schurer et al., 2020).

# 1.2 | TRAINING OF COMMUNITY HEALTH WORKERS

Community health workers generally follow a training before starting in their function. Most often this is not a formal medical education (Kok et al., 2017; Schurer et al., 2020), but rather a training that is adapted to their specific tasks. Depending on the program they will be working in, the training focuses on aspects like care coordination, health coaching, and/or providing social support (Hartzler et al., 2018).

Research has underlined that following training to become a community health worker has several positive outcomes. First, trainees develop skills related to their profession, such as communication (Javanparast et al., 2012), new knowledge on technical aspects in the field (George et al., 2017; Javanparast et al., 2012), and relevant health knowledge (Hill et al., 2017). Upgrading skills and knowledge is found important to motivate and gain retention of community health workers (George et al., 2017). Furthermore, understandings of community health workers' roles and functions are broadened (Javanparast et al., 2012). Second, by regarding community health workers as valued members of the healthcare team, they become empowered as individuals (Tulenko et al., 2013). Their social status increases (Kane et al., 2020), and their self-esteem (Kok et al., 2015) and confidence in their capacity to perform their responsibilities is boosted (Scott et al., 2018). Third, since they increase communication with the community (Javanparast et al., 2012) and gain capacity to facilitate community agency (Kok et al., 2015), empowered community health workers can in turn empower the health access and literacy of communities (Kane et al., 2016; Shrestha, 2003).

Regarding the format of the trainings for community health workers, different studies identify wide variations in duration and methodologies. Duration ranges from five hours to six months (Hill et al., 2017; Javanparast et al., 2012; O'Brien et al., 2009) and is offered by various institutions, from community colleges and non-profit organizations to academic researchers (O'Brien et al., 2009). Different educational methodologies are used, such as role playing, didactic sessions, mentored one-one learning, and follow-up assessments (O'Brien et al., 2009), often combining classroom theory sessions, practical exercises, and participatory sessions (Kok et al., 2015; Scott et al., 2018).

# 1.3 | INNOVATIVE WORK-TRAINING PROGRAM FOR COMMUNITY HEALTH WORKERS IN BRUSSELS

An innovative work-training program for community health workers was developed in Brussels by a local NGO EVA bxl, as part of the project "Culturally sensitive care ambassadors – valorizing talents +" (2016–2021) and financed by the European Social Fund. It was designed to address three urban challenges in deprived areas of Brussels: 1) migrant families living in the neighborhood excluded from care services; 2) home care services operating in the neighborhood lacking culturally competent care and outreach programs; and 3) neighborhood residents with a migration background facing high levels of unemployment yet often with invaluable expertise, who are not hired by healthcare organizations because of having disallowed educational certificates. The work-training program was carried out three times (in 2017, 2019, and 2020), every time with 10 different community health worker trainees. Each work-training program lasted nine months and consisted of courses on culturally competent care, communication, and Dutch language. Trainees also did an internship in care organizations during these nine months to gain practical experience and followed exchange workshops between community health workers and care professionals working in care organizations. Nine care organizations participated in the project. Strengths-based education was found to be an important success factor to engage and empower trainees. Previous experiences of trainees (e.g. in care or related to their cultural background) were actively engaged, shared, and seen as strengths (Hoens et al., 2021).

# 1.4 | RESEARCH QUESTIONS

In this qualitative study, the Most Significant Change technique (Davies & Dart, 2005) was used to evaluate the impact of a nine-month work-training program on trainees. This technique allows gathering a rich description of changes and captures unexpected changes. As this approach does not focus on predefined indicators but includes the lived experiences of participants to study the outcomes of an intervention, it captures process outcomes that are not documented by traditional evaluation methods (Wilder & Walpole, 2008). The technique also allows for the inclusion of outcomes that were personally valued by trainees and for outcomes they found most significant (Choy & Lidstone, 2013). While the Most Significant Change technique can start by defining domains of change, in this study we chose not to define domains of change prior to the data collection since we did not want to risk predefined domains shaping participants' answers, as likewise reasoned by Keinemans et al. (2020) and Aisiri et al. (2020). Three research questions were posed. The first two are answered based on story collection (i.e. through individual interviews):

- (1) What Most Significant Changes did trainees experience by following the Brussels' community health workers work-training program?
- (2) What are enabling and disabling factors to reach the Most Significant Changes, according to these trainees?

Among these initial stories, the Most Significant were subsequently selected (i.e. story selection in a focus group with community health workers) to answer the following research question:

(3) What factors influence trainees in the story selection of the most significant story?

# 2 | METHODS

# 2.1 | SAMPLING AND PARTICIPANTS

Sampling focused on those participants who followed the training and who could best describe what worked for them (Tonkin et al., 2021). In the Most Significant Change technique (Serrat, 2017), purposeful sampling with a bias in favor of success is often applied for the individual interviews, as one can learn from unusual, information-rich cases (Patton, 2015). To this end, program leaders selected and approached the community health worker trainees of the first two editions (2017 and 2019-2020) of the training. Those who were willing to participate in the research project were contacted by the interviewer (SH). For the focus group, all the trainees of the last edition (2020-2021)

were contacted by the program leaders to participate, yet not all were free to do so due to other obligations.

The study was conducting according to the guidelines of the Human Sciences Ethical Committee of the Vrije Universiteit Brussel (VUB), respecting the European Framework for Research Ethics (European Commission Directorate-General for Research and Innovation, 2012). The research process, with any possibly associated potential harm and discomfort, was reflected upon by a team of researchers. Since the study included competent human subjects who could provide informed consent, their privacy was not invaded and no experiments were carried out, no additional approval was required by the committee (Vrije Universiteit Brussel, 2021).

Table 5 presents an overview of the participant characteristics. While 89% of the community health worker trainees involved in the project were female, all respondents were female and no male respondents were found.

| Year of training | Interview period | Country of origin    | Participated in |  |
|------------------|------------------|----------------------|-----------------|--|
| 2017             | November 2020    | Cameroon             | Interview 1     |  |
| 2017             | November 2020    | Morocco              | Interview 2     |  |
| 2017             | November 2020    | Nigeria Interview    |                 |  |
| 2019-2020        | June 2020        | DR Congo Interview 4 |                 |  |
| 2019-2020        | June 2020        | DR Congo             | Interview 5     |  |
| 2019-2020        | June 2020        | Tunisia              | Interview 6     |  |
| 2019-2020        | November 2020    | Guinea               | Interview 7     |  |
| 2019-2020        | December 2020    | Guinea               | Interview 8     |  |
| 2019-2020        | December 2020    | Morocco              | Interview 9     |  |
| 2020-2021        | January 2021     | DR Congo             | Focus group 1   |  |
| 2020-2021        | January 2021     | Somalia              | Focus group 1   |  |
| 2020-2021        | January 2021     | Guinea               | Focus group 1   |  |
| 2020-2021        | January 2021     | Nigeria              | Focus group 1   |  |
| 2020-2021        | January 2021     | Morocco              | Focus group 1   |  |
| 2020-2021        | January 2021     | Morocco              | Focus group 1   |  |
| 2020-2021        | January 2021     | Morocco              | Focus group 1   |  |

#### **TABLE 5** Participant characteristics

# 2.2 | DATA COLLECTION AND ANALYSIS

The Most Significant Change consists of two steps: story collection and story selection (Davies & Dart, 2005).

#### 2.2.1 STORY COLLECTION: INDIVIDUAL INTERVIEWS

In the first step of the Most Significant Change technique, individual stories of participants were collected to describe changes brought about by the training through individual interviews (N=9). This enabled respondents to reflect on their experiences and gained benefits (Davies & Dart, 2005). Nine stories were collected between June 2020 and December 2020. Eight interviews were conducted online using WhatsApp videocall because of social restrictions imposed in light of the COVID-19

pandemic. One interview was conducted face-to-face because the respondent felt uncomfortable with an online interview; to this end, safety measures were undertaken and government COVID guidelines respected. The interviews lasted between 32 and 60 minutes, with a mean of 46 minutes. Interviews were conducted in French, English or Dutch, depending on the language spoken by the interviewee. The interviewer spoke all three languages. A semi-structured interview guide was developed, based on the Most Significant Change guidelines (Davies & Dart, 2005), and discussed between the co-authors. The main interview questions were: "When you look back at your training as a community health worker, what has been the most important change you attribute to the training?", "What has caused this change?", and "What difference will this change make for you in the future?". Before the interview, the interviewer first explained the objectives and procedure of the data collection, whereafter written informed consent was obtained from all participants using a Qualtrics survey or a written form for the face-to-face interview.

These individual interviews were transcribed verbatim and analyzed using thematic analysis to review all individual stories. The following steps were followed: 1) becoming familiar with the data; 2) generating initial codes; 3) searching for themes; 4) reviewing themes; 5) defining and naming themes; and 6) writing up the report (Braun & Clarke, 2006). The emerging themes were coded inductively, using new information that came out of the data with MaxQDA software. Themes for emerging changes included developing competence, enlarging social networks, and gaining social recognition. The first author was primarily responsible for completing the analysis, but obtained feedback from the co-authors on a regular basis to deepen the analyses. This process ensured validity of the results.

#### 2.2.2 STORY SELECTION: FOCUS GROUP

In the second step of the Most Significant Change technique, the Most Significant Change story was selected. To this end, the nine stories coming from the interviews of the first step were written down as separate, concise stories. Small adjustments (use of language, pseudonymization) were made in order to present a comprehensive story and enable discussion in the focus group. The focus group discussion was held in January 2021 to talk about these captured stories in a horizontal selection process, during which stories were selected by other trainees. This process gives more weight to participants' priorities (Tonkin et al., 2021) and is therefore a useful tool when the impact on the users is identified, as opposed to vertical selection which is made by employers higher in hierarchy (Keinemans et al., 2020).

During the focus group, respondents were asked to explain their reasons for selecting a particular change story (Davies & Dart, 2005). The main interview questions were: "What do you consider as the most significant story and why?", "In which story do you recognize yourself and why?", "Which changes did you also notice yourself?". Seven participants of the training year 2020-2021 (see Table 5) were included in the focus group, which lasted 120 minutes and was conducted in a mix of English, French and Dutch. Participants were used to this multi-language context, as the mix was also used during the training program. When necessary the moderator or other respondents translated. Following the same procedure as the individual interviews, written informed consent was obtained from all participants.

The story selection is considered as a data analysis itself (as also conducted in Budiawan et al. (2020) and Aisiri et al. (2020), and discussed in Tonkin et al. (2021)). Story selection was conducted using the following four steps: first, during the focus group discussion each participant read the nine

stories independently and selected four stories representing the Most Significant Change according to them. All stories were discussed, while each participant identified their chosen stories and explained the reasons for their choice. Second, all participants voted for one most significant story. The story with the most votes was regarded as most significant. Although the name 'Most Significant Change' might suggest otherwise, the primary goal was not to select the one story that showed the most significant impact – rather, the criteria and arguments in the selection process were as important as the selected stories (Keinemans et al., 2020). Third, this selection process was discussed by the participants. Last, the results were reported to the program coordinators and steering committee to enable them to adapt future trainings.

# 3 | RESULTS

# 3.1 | TYPES OF SIGNIFICANT CHANGES

The thematic analysis of the individual interviews revealed four types of significant changes experienced by the participants: 1) increased knowledge, social skills, and attitudes relevant for care provision and personal development, 2) facilitated employability, 3) enlarged social networks, and 4) gained social recognition.

3.1.1 INCREASED KNOWLEDGE, SOCIAL SKILLS, AND ATTITUDES RELEVANT FOR CARE PROVISION AND PERSONAL DEVELOPMENT

First, an increase in **knowledge** of the care services was mentioned by the participants as an important change. Participants got to know the care sector and more specifically the care offering that existed in Brussels, which was often new to them: "Before, I didn't know what existed. Now I know many addresses. Because I didn't know Brussels except for where I live, I cannot say that now I know all the communes, you can't know everything, but in most of them I know a lot of things." Other changes were mentioned by participants in terms of familiarity with different cultures and their specific beliefs and customs (e.g. taking off one's shoes before entering someone's home).

Second, improving **social skills** (i.e. being aware of how to communicate with others) was mentioned. Participants mentioned that they acquired skills on how to approach people ("*I know now how to talk to people*") and refer them to the appropriate services: "After the training, it becomes something *natural when you see an older person, you are not completely stressed anymore, it doesn't bother you, you say to yourself: 'yes, I've already done the training, they taught me how to go and talk to a person'. We learned how to communicate, how to show interest in the person, the distance that you must have to not invade their intimacy. Now when I see an older person, I know how to approach them.*"

Third, **attitudes** on being sensitive and approachable were stimulated throughout the training. Participants experienced that the training stimulated their courage and self-confidence in encounters with other people: "I learned to have confidence in myself. In the beginning I was a bit reserved, but then I became more relaxed." Additionally, community health workers expressed they became attentive to people in need of care and were approachable to residents in their neighborhood: "The training opened my eyes. When I go out, I see older people and my intention is to know whether they have people around them. You immediately see whether a person needs help by the way they are dressed. My impulse now is to say hello to them and if possible ask questions, do they need help, do they have people around them or something like that."

#### 3.1.2 FACILITATED EMPLOYABILITY

Community health workers indicated that the training contributed to their employability. First, some participants discovered their interests for a future job. For some this could be working with older people, for others a caregiving profession working for other target groups. A participant explained that doing the training reinforced her idea of working with children: "Before following the training I already wanted to work with children, but I wanted to give working with older persons a try. I learned a lot and discovered that it's not a job for me."

Another change mentioned by the community health workers was that at the end of the training an important portion of the participants felt prepared to work as a community health worker. One participant told: "I am ready to practice the profession of community health worker. I have the idea to open an office in the neighborhood, in this way we are visible and people who have a need can easily find us."

#### 3.1.3 ENLARGED SOCIAL NETWORKS

The community health worker trainees shared a lot about their personal and professional lives with each other, which ensured very close contacts: "We created a WhatsApp group. Here we shared for example pictures of our children and then everybody was happy for us. Or when someone got married, she shared pictures with us. I said to myself: 'if people don't mean anything to you, you're not going to explain all this, you're not going to show them all this.' So I felt that I mattered to them." For some participants this expanded their social networks. A participant who arrived in Belgium only two years before the training explained: "It was a great group, we were friends, it was like a family. We shared a lot and it was good."

Some participants told that they received support from the project coordinators and teachers, even after they completed the training. Community health workers felt supported by them in looking for adequate jobs or trainings: "The most important thing is that they gave me a family. Because they call us on the phone to see if we're okay, what we want to do, you want to find a job, they'll help you, they're there. If you have difficulties doing something, they always say 'call me and tell me if I can help, I'll do it'. That's already encouraging. They also tell you if you want to do another training, they will find one for you. They are behind the people, it's not that when you've finished the training it's over, you're left alone." Others felt supported in concerns that came along with the training, but also outside the training, such as administrative tasks or child care.

#### 3.1.4 GAINED SOCIAL RECOGNITION

Some participants highlighted that gaining social recognition from community members was their Most Significant Change. They felt recognized as key figure in the neighborhood who people easily contacted for questions and help. A participant explained how she helped people access information and how without her they wouldn't have found any help: "On my Facebook account I always post things related to trainings, so people get in touch with me if they want to do a training. I tell them where to go. So they know they can come if they are in need of information. I had a friend who was really sick and I told her to go to the insurance and ask for help. And now she has someone that comes to her house to help her with cleaning, ironing, and things like that. If it were not for me, she wouldn't have gone."

#### 3.2 | ENABLING AND DISABLING FACTORS TOWARD CHANGE

Three enabling and one disabling factor toward these changes were discussed by the participants: mentoring, peer learning and peer support, experience-based learning, and the difficulty of building trust.

### 3.2.1 ENABLING FACTOR 1: MENTORING

Participants experienced the mentoring during the training through the attentiveness of the instructors to their needs and by sharing experiences, encouragement and feeling supported. First, instructors were **attentive and responsive to participants' needs**. This ranged from making sure everyone was keeping up during classes to listening to concerns and discovering whether participants needed some extra help: "They [instructors] listened to us and would help with everything. If you had a problem, you could explain it. Even if it was not about the training, they would help us. But above all, the listening and patience was really remarkable to me." The informal moments organized by the instructors likewise ensured an open contact toward participants, for example by organizing farewell parties and dinners after class.

Second, participants felt motivated and encouraged by the internship mentors. These mentors often **shared their own experiences** of the work field. Several participants expressed that they valued the mentors' knowledge and were inspired by their stories: "She [internship mentor] inspired me because in the beginning I didn't really know what I wanted to do in the care sector. But while working with her she assisted me, she inspired me. I also want to be a nurse like her." Additionally, the internship mentors **encouraged** participants to go beyond their limits, encouraging them to learn and do new things in the workplace: "She [internship mentor] has a lot of experience with older people. She went with me to work to add color, add spice to what I was doing. Where she saw that I was limiting myself, she would say 'no, we need to move on a bit'."

Third, participants felt supported by the project coordinators. Especially the informal contact after completing the training gave them the feeling that someone was thinking about them and **supporting** them: "We didn't feel alone. We felt that there was someone we could go to. With questions, with problems, with everything we were facing during the day. We didn't feel abandoned in fact."

#### 3.2.2 ENABLING FACTOR 2: PEER LEARNING AND PEER SUPPORT

Throughout the interviews, several participants emphasized the importance of both formal and informal peer learning. During classes (formal mode of peer learning and peer support), time and space was provided for participants to share their own experiences about their background, culture, internships, daily experiences, etc.: "We did the internships, so each one had their own experiences. And when we came back to class, we discussed it all. We discussed how to handle a situation. We shared experiences and we learned from each other." Also after the classes, participants were regularly in contact with each other and made everything discussable (informal mode of peer learning and peer support): "When we started the training, it was different. There were all the ethnic differences between us. But we talked and we felt that for the classmates who had difficulties we could find solutions. We would say, 'Oh yes, you have this problem, don't worry, try if this will help you'."

#### 3.2.3 ENABLING FACTOR 3: EXPERIENCE-BASED LEARNING

Experience-based learning (Kolb, 1984) puts the experiences of participants at the center of training while also providing opportunities for reflection. Experiences that gave more insights into care practices were considered as valuable by participants. The majority of participants had **previous experience providing care** to family members or neighbors, or through jobs they had back in their country of origin. Both these experiences showed to be of great importance to them: "*I had my* 

experience as a family assistant and a lot was already there, but not on the surface. There were a lot of things that I didn't know while I was working. But when I did the training, I was able to do a lot of things better."

Also during the training, an important component was to gain practical experience. This could be through **visiting** care centers and local organizations together with the instructors and other participants. In this way, participants got to know new organizations and experienced the caregiving atmosphere. Throughout the interview it became clear that such real-life experiences sticked in their minds for a while: *"The visits were also important, it's impossible to forget what we saw during the visits. In class, we sometimes laughed or forgot the things we learned. But during the visits we saw things that were painful sometimes, like a person suffering from an illness. Visits could also result in beautiful and touching moments."* 

Another way to gain more practical experience was through **internships**, where participants got in touch with a concrete practice and were in direct contact with older adults: "I remember everything, but the most interesting was the internship. When I practiced the training in the internship, when I visited older people or called them on the phone, I learned the little details."

Learning kept going even after the training was completed. Some participants mentioned that they acquired more practical experience because they found a **job** in the care sector afterwards. Throughout this job they were putting the theory into practice and this enforced their experience: "In the training I learned the theory, now in my work I'm doing the practice. Like networking, I learned it in the training."

# 3.2.4 DISABLING FACTOR: THE DIFFICULTY OF BUILDING TRUST

Some participants experienced difficulties in contacting older people and practicing what they had learned during the training. They said it needed a lot of courage to approach and contact people in the neighborhood, especially when you don't know them: "In the beginning it was difficult, but afterwards you're thrown into it, it's not difficult at all. You learn it fast. But I had never worked and I never had the courage to face people." These participants argued they needed patience to build trust with older persons in the neighborhood, which often required time. In this sense, they did not always see an immediate result of their work: "Older people are afraid and so I didn't like the courses we did outside (to learn to approach people). All day long and then I could not help anyone, I find it's a waste of time."

#### 3.3 | STORY SELECTION

The participants in the focus group voted for the story they found the most significant. Out of nine stories, the four stories with the most votes are described here, together with the reasons why participants voted for them. Indicators why participants valued certain stories were recognizability, inspirability, and admirability.

3.3.1 STORY OF DANIELLA: I GOT TO KNOW BRUSSELS, ITS WELFARE ORGANIZATIONS, AND MYSELF Daniella explained that she did not know Brussels before and because of the training she got to know the city and its welfare organizations. She learned where to go when people needed help. In the future Daniella wants to work with children since this has always been her dream. Through this training, she wanted to explore whether she also liked working with older people.

Focus group participants chose this story because they recognized themselves in getting to know the different welfare organizations. Additionally, they highlighted the importance of figuring out what they would like to do as professionals in the future: "She realized that working with older people is not for her because of the training. So it highlights the importance of this kind of training, that people know where to go. I find that all the participants, they are all mothers who don't have time to waste, they have to take care of their families. And so this kind of training teaches them to know directly 'this is for me, this is not for me'. That's why her story appealed to me."

#### 3.3.2 STORY OF ADRIANA: I GAINED CONFIDENCE IN MYSELF

In the beginning Adriana indicated she was a shy person, and slowly she got more confidence and courage. The training and her internship mentor gave her a boost and she even made appointments with patients herself during the internship.

The story of Adriana was selected because the training contributed to her self-confidence, which was considered as very valuable by the participants. All of them could relate to the story and pointed out that they all became more confident through the training. A participant explained how she once felt how important it is to be confident: "It's hard to approach people. You have to be confident. And this training also helps. Like for me, for example, last time when I was doing the internship, I was blocked because I couldn't find my words. I was on the phone and didn't know what to say. Normally I talk with French speakers, but this time it was with a Dutch-speaking Turk, and I was stuck. So my mentor helped me and asked me how I was going to do it next time. So you need to have confidence."

# 3.3.3 STORY OF JULIE: I BECAME SENSITIVE TO PEOPLE IN NEED

Julie discovered that there are people in her own neighborhood who are isolated and need help. During the training she became sensitive to this and approached these people to start a conversation. She felt the support from her supervisor to push her limits. Now she feels ready to work as a community health worker.

The story of Julie was primarily selected because at the end of the training she had a goal and participants found this inspiring. She felt ready to work as a community health worker and had the idea to open an office in every neighborhood, which implies that she wanted to start a care organization located in the neighborhood. The participants supported this idea: "She (Julie) finished the training being ready to open an office to help others. That's what interested me the most. So she didn't do a training for nothing, she finished it with a purpose. We all have the goal to help people and opening an office is a good idea."

#### 3.3.4 STORY OF MARYAM: I LEARNED HOW TO DEAL WITH OLDER PEOPLE

While growing up, Lydia took care of her grandparents. Through the training she built experience in how to care for older people she doesn't know. She learned how to gain their confidence and communicate with them. During her internship she had some disagreements with colleagues and therefore realized the importance of having a good relationship with her peers. Even though this was sometimes difficult, she learned how to stay professional in these relationships.

This story was chosen by the participants as most significant because they recognized that a relationship of trust with older persons is necessary in order to help them with certain needs. They also appreciated how she felt compassion toward older persons and how she knew how to approach them: "She knows the warmth that people need. For example, you come to someone who is aggressive but that is not against you, it is because that person has problems. And she knows how to approach people." Additionally, her professionalism to cope with relationships with colleagues was admired.

# 4 | DISCUSSION

The role of community health workers is to make the link between healthcare providers and community members (Delgado, 2020; Shommu et al., 2016). This study has evaluated the impact of a nine-month work-training program on community health workers by investigating the types of significant change they experienced themselves, and the enabling and disabling factors leading to these changes.

Four types of significant change can be identified: 1) increased knowledge, social skills and attitudes relevant for care provision and personal development, 2) facilitated employability, 3) enlarged social networks, and 4) gained social recognition. These mentioned changes highlight that a work-training program for community health workers should not only focus on work-related competences, but also on broader life skills and social capital. For the first type of change, Sharma et al. (2021) underline the importance of life skills in their research on a training program for life skills education and financial literacy among community health workers in India by defining life skills as communication skills and self-confidence. They also mention other skills that were less prominent in our study: problem-solving, decision-making, and time and stress management skills. For the last types of change, regarding expanded social networks and social recognition, social capital empowers an individual to enact change and advance their position while also providing opportunities to improve community members' health (Saint Onge & Brooks, 2021).

When it comes to enabling factors, the role of mentoring proves to be of the utmost importance, through instructors' attentiveness and responsiveness to participants' needs, talents, and expertise; sharing of experiences; and encouragement and support of participants. The role of the instructors, internship mentors, and project coordinators has many similarities with "mentoring as befriending" and "mentoring as coaching" as described by Pawson (2006). Mentoring as befriending in our training program implies creating trust and sharing experiences. Mentoring as coaching entails stimulating trainees to go beyond their limits and encouraging them to learn new skills.

The disabling factor of the difficulty of building trust shows that the role of community health workers to build a bridge with the community, to contact people in the neighborhood, is not as easy as it seems despite it being extensively described in literature as one of the main goals for community health workers (e.g. Delgado, 2020; Shommu et al., 2016). Building trust is an evolving and long-term process. It is related to both the training and quality of work of community health workers and to organizational support, as this provides space for open dialogue and engagement (Gilson, 2003). Important components of organizational support are supportive supervision and accompaniment. This means that the mentor accompanies the community health worker and to be able to address these challenges later, during the training. In this way, community health workers are supported to build their own confidence and build trust with community members, instead of having to figure it out on their own (Singh et al., 2015). Moreover, building trust contains a constant workers' reflection about when and how to approach people in the community, as it often includes a vulnerable population (Anstey Watkins et al., 2021).

Based on these findings, implications for social work practice can be formulated. Since both social workers and community health workers are working in communities to increase health and care, they can make effective interprofessional teams (Berrett-Abebe et al., 2020; Feltner et al., 2012).

Therefore, the results of this study are important for social workers who are interested in partnering up with community health workers, especially the enabling and disabling factors as defined above should be taken into account by social workers. A social worker could for instance take the role of mentoring, by being attentive and responsive to community health workers' needs. Additionally, the disabling factor of the difficulty of building trust might also be experienced by social workers. In the role of mentor and through own experiences, the social worker can support the community health worker in this difficulty.

While conducting this research some limitations became apparent. First, the group of respondents had various native languages. This meant that the interviews were often conducted in a second language, i.e. French, English, or Dutch. Although the researcher's and the interviewees' language skills might have affected the dynamics in various ways (e.g. misunderstandings, interviewer and response bias, missing of important cues such as non-verbal communication or nuances) (Marschan-Piekkari & Reis, 2004), these issues were reduced in different ways. One was that the interviewer (SH) spoke the three languages and therefore a translation was not needed for data analysis. In this way, original nuances and subtleties were not lost. Additionally, prior to the interview the interview questions were examined for wording and understandability (through discussion with the co-authors). Also, the interviewer and respondents could ask clarifying questions as needed.

Second, during the story collection it turned out to be difficult to unravel disabling factors toward change that were hidden in the individual stories of the community health workers. Only one disabling factor could be identified – the difficulty of building trust. This could be because the Most Significant Change holds a bias in favor of success (Davies & Dart, 2005; Serrat, 2017). The vast majority of collected stories in this study contained positive changes. This should however not necessarily be a limitation, since identifying positive changes could help move the program toward more of these positive changes (Davies & Dart, 2005).

Third, performing the phase of story selection with peers, fellow community health workers, was challenging. As some questions required analytical thinking, such as "why is this story significant?", we are not sure whether horizontal story selection was the most appropriate method in the end. Given the community health workers' close involvement with the program, it was difficult for them to reflect on the process, therefore new perspectives of stakeholders (e.g. project coordinators, instructors, internship mentors, care professionals) might have enriched this reflection. In particular, the question "why is this story not significant?" was rarely answered. Other researchers (e.g. Keinemans et al., 2020; Wilder & Walpole, 2008) acknowledge the difficulty of getting to the depth structure of the arguments for story selection. Nevertheless, we feel that the value of the community health workers' involvement in the data analysis process cannot be underestimated, because of its power to unravel the perspectives of the participants and their reasoning. Keinemans et al. (2020) suggest that a confrontation of stakeholder arguments might contribute to a more thorough understanding of the relevance of the program. We would therefore advise including both horizontal and vertical story selection in the future, this is to say including story selection with both community health workers and stakeholders.

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# COMMUNITY HEALTH WORKERS AND CULTURALLY COMPETENT HOME CARE IN BELGIUM: A REALIST EVALUATION

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# CHAPTER 6. COMMUNITY HEALTH WORKERS AND CULTURALLY COMPETENT HOME CARE IN BELGIUM: A REALIST EVALUATION

# ABSTRACT

This qualitative study investigates through a realist evaluation how the work training programme of 10 community health workers (CHWs) contributed to culturally competent home care services. A European Social Fund project trained 10 jobseekers with migration backgrounds to become CHWs in Brussels (Belgium). Three research questions were formulated: (1) What increase in the cultural competence of the home care organisations can be identified at the end of the project? (2) How did the training contribute to this increase? (3) Which factors and preconditions made the positive outcomes of the training more likely? This study analysed 10 mid-term interviews with individual CHWs in training and four focus groups at the end of the project with CHWs, care employees, trainers and project coordinators (N=25). First, the results showed that the increase in cultural competence was located mostly on the surface structure of the organisation (e.g. adapting communication materials) and not in its deeper structure. Second, the principles of strengths-based education proved to be important during the training (e.g. getting to know, recognise and address the competences and skills of the CHWs). Third, contextual factors at the micro-level (e.g. interest in care and cultures), the exo-level (e.g. management culture) and the macro-level (e.g. policy regulations) could foster or hinder the process of increasing cultural competence. This paper concludes that although the project contributed to a shift in organisational culture towards cultural competence, it remains challenging to effect a similar shift in the deep structure of care organisations.

# **KEYWORDS**

Community health workers, culturally competent care, older adults with migration background, home care services, work training programme, accessibility to care

# 1 I INTRODUCTION

The number of older adults with a migration background in Brussels (Belgium) is rising sharply. By 2020, this group will make up more than one-third of the Brussels population of over-65s. Although researchers predict that the demand for formal care will increase among this group, as a supplement or replacement for informal care (Fokkema et al., 2016), at this time, older people with a migration background make almost no use of home care services and remain very difficult for professional home care providers to reach (Suurmond et al., 2016). Barriers are constituted by language, low health literacy and knowledge of the healthcare system, lack of social networks facilitating access to timely care, and insecurities related to intercultural encounters, in which inadequacy on the part of care organisations in addressing migrants' needs plays a role (Ahaddour et al., 2016; Kristiansen et al., 2016).

To improve accessibility, research has called for more culturally competent care services. Cultural competence is a complex concept (Gebru & Willman, 2010; Hemberg, 2019; Henderson et al., 2018; Long, 2012) and is commonly understood as "the dynamic and evolutionary process of acquiring the ability to provide effective, safe, and quality care to individuals from different cultures, along with considering the different aspects of their cultures" (Sharifi et al., 2019, p6). Conceptualising cultural competence in greater detail, Sharifi et al. (2019) developed a model based on the six most common attributes of cultural competence: (1) cultural awareness (understanding, identifying and reflecting on the similarities and differences of cultures and one's own prejudices), (2) cultural knowledge (continuously acquiring information about different cultures), (3) cultural sensitivity (valuing, respecting and admiring cultural diversity), (4) cultural skills (facilitating effective communication between individuals from different cultures) (5) cultural proficiency (seeking knowledge about cultural competence and developing new therapeutic approaches based on culture, reflecting a commitment to change), and (6) dynamicity (becoming culturally competent through frequent encounters with different older adults).

The introduction of community health workers (CHWs) is often studied as a means to improve care and the accessibility of care services. The most widely accepted definition of CHWs is provided by the American Public Health Association (2020):

CHWs are frontline public health workers who are trusted members of and/or have an unusually close understanding of the community served. This trusting relationship enables CHWs to serve as a liaison/link/intermediary between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery.

Research has shown that CHWs improve the health knowledge of community members and increase care utilisation (Andrews et al., 2004; Swider, 2002). However, little is known about the broader impact of CHWs in making the home care organisation culturally competent, and research is needed to establish which components make the training of CHWs effective (Verhagen et al., 2013). In addition, Sharifi et al. (2019) have identified a need for more research on education for culturally competent care and the role of healthcare organisations therein.

Education for culturally competent care can be organised according to the principles of strengthsbased education. Strengths-based education identifies, recognises and affirms the strengths of students as a means of motivating them and allowing them to excel. It is guided by five educational principles: (1) measuring strengths, achievements and determinants of positive outcomes to enhance these strengths; (2) individualising learning experiences by tailoring training to student needs and interests, highlighting their qualities and providing feedback; (3) networking for praise and recognition, so that students discover their strengths and share this new information, and that in building strengths the best talents can be brought together; (4) deliberately applying strengths within and outside the classroom, giving students opportunities to explore/practice their strengths; and (5) intentionally developing strengths through novel experiences to expose students to information, resources and opportunities for heightening their skills and knowledge (Lopez & Louis, 2009).

To respond to the need of home care organisations to provide culturally competent care in a super-diverse neighbourhood, a work training programme with CHWs was developed. Jobseekers with a migration background were trained to become CHWs in order to increase the accessibility of home care services and improve their cultural competence.

This qualitative study uses a realist evaluation to address the questions of what works, how, for whom and under which circumstances (Dalkin et al., 2015). It explores the perceptions of key stakeholders in a European Social Fund (ESF) project within which a work training programme for CHWs was developed to create culturally competent home care organisations. The realist evaluation uses a context-mechanisms-outcomes (CMO) configuration to include the outcomes, mechanisms and context of the project (Dalkin et al., 2015). Three research questions were posed to create this configuration:

- Outcomes: What increase in the cultural competence of the home care organisations can be identified at the end of the project?
- Mechanisms: How did the training contribute to the increased cultural competence of home care organisations?
- Context: Which factors and preconditions made the positive outcomes of the training more likely?

# 2 | METHODS

## 2.1 | THE SETTING

Within a ESF's call, the 'Innovative neighbourhood care model tailored to a vulnerable neighbourhood' project (2016–2017) was developed. The project was designed to address three challenges in deprived urban areas of Brussels: (1) migrant families living in the neighbourhood are excluded from care services; (2) home care services operating in the neighbourhood lack culturally competent care and outreach programmes; and (3) the neighbourhood residents with a migration background face high unemployment. To adapt to these challenges, 10 people with a migration background and experience or great interest in care were recruited as CHWs to a work training programme. The nine-month programme consisted of courses on culturally competent care and the Dutch language, an internship in a home care organisation, and formal exchange moments between CHWs and care employees. In addition, a five-day training course on culturally competent care was organised specifically for care employees. Five home care organisations participated by sending employees to the five-day training course and offering internships to CHWs.

# 2.2 | DATA COLLECTION

To understand the multiple perspectives of stakeholders of the project, purposeful sampling was used. All stakeholders were given a chance to participate, however not all could be present. Four participant groups were included: (1) CHWs who followed the full training programme, (2) care employees who followed the five-day training course on culturally competent care, (3) trainers from both training events, and (4) project coordinators of the participating home care organisations. Qualitative data were collected in April 2017 and October 2017. Ten individual interviews with CHWs were conducted halfway through the project, and four focus groups with the four participant groups (N = 25) were conducted at the end of the project. The individual interviews lasted between 30 minutes and 120 minutes. The focus groups lasted between 116 minutes and 140 minutes. Both the interviews and focus groups were conducted in Dutch, French or English at the premises of a local NGO. Some participants who could not attend the focus groups were engaged in an email interview (Burns, 2010).

#### 2.3 | DATA ANALYSIS

All the interviews and focus groups were audio-recorded and transcribed verbatim. In the first step, the CMO configuration (Pawson & Tilley, 1997) was developed deductively based on a review of the literature (Marchal et al., 2010) and establishes an overview of the outcomes, mechanisms and context. First, the outcomes (Pawson & Tilley, 1997), i.e. the effects triggered by the mechanisms and context, were categorised by applying the six attributes of Sharifi et al. (2019) model of cultural competence as main labels. Second, the mechanisms (Pawson & Tilley, 1997), i.e. the different components of the project, were categorised using the five principles of strengths-based education formulated by Lopez and Louis (2009). Third, the three main labels for the context (Pawson & Tilley, 1997), i.e. the setting in which the project was put into practice and which determined whether the project worked, were developed in accordance with Bronfenbrenner's (1979) ecological model. This model clarifies the interaction of an individual with the environment and describes different levels that affect individual behaviour: (1) micro-contextual factors (i.e. the capacities of individual CHWs), (2) exo-contextual factors (i.e. the role of organisations in affecting behaviour) and (3) macro-contextual factors (i.e. the broader impact of culture, values, norms and policy) (Bronfenbrenner, 1979).

In the second step, the data were analysed in line with the thematic analysis techniques of Braun and Clarke (2006), using MaxQDA software. This consisted of: 1) becoming familiar with the data; 2) coding interesting features of the data (This process was mainly done deductively, building on the insights of the literature of the CMO configuration as described in the first step. However, other codes came out inductively); 3) searching for themes; 4) reviewing themes; 5) defining and naming themes (such as surface and deep structure in outcomes); and 6) writing up the report (Braun & Clarke, 2006).

In the third step, the new information derived from the collected data (as found in step 2) was further integrated into the final CMO configuration (building further on the table of step 1), resulting in table 7.

The first author led this process, while the co-authors provided feedback and discussed discrepancies. Throughout the project, regular meetings were held with the ESF project steering group

to discuss the progress and research design, review the preliminary results, and make adjustments. The objective was to shape the research in a participatory way and to include reflections and new questions in the course of the research. The inclusion of different researchers and project members also contributed to this research's objectivity, thereby ensuring credibility and confirmability of the findings (Guba & Lincoln, 1982).

# 2.4 | ETHICAL ASPECTS

The study was conducted according to the ethical guidelines of the Declaration of Helsinki (World Medical Association, 2013). A team of researchers, including the authors, reflected on research process and potential harm and discomfort. Participants were informed about the details of the study through an informed consent, which included the broader objectives of the study, participants' right to withdraw from the study, data governance and information on confidentiality. All participants gave both their written and verbal consent for an audio-recorded interview. To gain confidentiality, identifiable information of participants was removed in the data analysis process (e.g. names and places). The study followed the guidelines of the Human Sciences Ethical Committee of the VUB, respecting the European Framework for Research Ethics (European Commission Directorate-General for Research and Innovation, 2012). Since the study included competent human subjects who could provide informed consent, no minors were involved, participants' privacy was not invaded and no experiments were carried out, no additional approval was required by the committee (Vrije Universiteit Brussel, 2021).

# 3 | FINDINGS

The participants of this study were CHWs, care employees, trainers and project coordinators (Table 6). Twenty women and five men participated. The CHWs had diverse national backgrounds (e.g. Syria, Cameroon, Pakistan and Rwanda). Their ages ranged from 25 to 56.

The findings (Table 7) are presented under the following headings: Outcomes, Mechanisms, Context, and What works in which context.

| Participants              | Men | Women | Job description         | Individual | Focus | Email     |
|---------------------------|-----|-------|-------------------------|------------|-------|-----------|
|                           |     |       |                         | interview  | group | interview |
| Community health          | 2   | 8     | Community health        | x          | x     |           |
| workers (CHW)             |     |       | worker                  |            |       |           |
| Care employees (CE)       | 1   | 5     | Staff member diversity, |            | x     |           |
|                           |     |       | Work contracts          |            |       |           |
|                           |     |       | coordinator, Carer,     |            |       |           |
|                           |     |       | Coordinator local       |            |       |           |
|                           |     |       | service centre          |            |       |           |
| Trainers (T)              | 0   | 2     | Teacher                 |            | Х     |           |
| Project coordinators (PC) | 2   | 5     | Management, Policy      |            | Х     | Х         |
|                           |     |       | officer                 |            |       |           |

#### **TABLE 6** Participant characteristics

| CONTEXT   | MECHANISM   | OUTCOME  |
|---|---|--|
| <ul> <li>Micro-level</li> <li>Interest in a caring profession and its cultural aspects</li> <li>Previous experience with care and diverse cultures</li> <li>Exo-level</li> <li>Workplace prospects after training</li> <li>Extent of opportunity for active participation</li> <li>Macro-level</li> <li>Support of the government</li> <li>Support of the home care organisation</li> </ul> | <ul> <li>Measuring student characteristics</li> <li>Diverse migration backgrounds among participants</li> <li>Previous experience or interest in care</li> <li>Individualising the learning experience</li> <li>Engaging the knowledge and experiences of the participants and highlighting their strengths</li> <li>Sharing practical examples of care among different cultures</li> <li>Taking into account the life stories and motivations of the participants</li> <li>Learning support from the project coordinator</li> <li>Networking for praise and recognition</li> <li>Discovering own network</li> <li>Learning methods to broaden the network</li> <li>Sharing knowledge and experiences with care employees</li> <li>Deliberately applying strengths within and outside the classroom</li> <li>Take-home assignments</li> <li>Spontaneous work as CHW</li> <li>Interntionally developing strengths through novel experiences</li> <li>Field visits</li> <li>Internship</li> </ul> | <ul> <li>Cultural awareness</li> <li>Reflecting on own cultural values and beliefs</li> <li>Learning to reflect on own care services</li> <li>Cultural knowledge</li> <li>Being open to acquire more knowledge about various cultures</li> <li>Learning about shortcomings in care services and barriers for older people with a migration background</li> </ul> |

TABLE 7 Summary of the CMO configuration for the training of CHWs on culturally competent home care organisations

# 3.1 | OUTCOMES

The participants indicate different aspects that are categorised in the results under the following outcomes, inspired by Sharifi et al. (2019) model of cultural competence: (1) cultural awareness, (2) cultural knowledge, (3) cultural sensitivity, (4) cultural skills, (5) cultural proficiency and (6) dynamicity.

First, in terms of **cultural awareness** employees reported that during and because of the project they reflected on their own identity by sharing and discussing with the other trainees their own and community's values, vision, perceptions on lifestyle (e.g. their own way of living, familial relationships) or own perceptions of care and ageing (e.g. can a woman be washed by a man). They also learned to reflect on the culture and values of their own care service (f.e. through exercices as 'If you were the manager, what would you change in terms of cultural competence?' and reflecting on 'How do we approach people as an organisation?'). In the words of one project coordinator:

'Exploring different truths. We have our ways of doing things, but the awareness that there are different truths is created.' (PC4)

Second, regarding **cultural knowledge** participants mentioned that they learned the importance of getting to know customs, traditions and beliefs of various cultures. A project coordinator explained what this cultural knowledge entailed:

'We have to teach our employees how to cook Halal, how to give intercultural care. And other things too, how to enter people's home, like taking off their shoes, how to deal with men and women patterns. These are all things that have to be taken into account.' (PC2)

However, the participants were aware that it was impossible and undesirable to know all specifities of all cultures. It was more important to be open and willing to get to know a culture, as a project coordinator explained:

'You cannot learn all the languages that exist, that is a bit difficult. Also cooking, you cannot endlessly learn about all types of cuisines. It is about an attitude of how are we going to try to meet your demand together and how are we going to solve it together.' (PC5)

By getting more insights into various cultures, they also learned the shortcomings and barriers towards their care services, f.e. the need for outreaching to the community.

Third, in terms of **cultural sensitivity** care employees spoke of gaining greater understanding, a more open attitude and respectful curiosity in dealing with older people with a migration background. One participant described being more alert to culturally sensitive elements:

'It's a reflex that you ask everyone, how's that within your community? How do you do that? Or how was that with you? There's a history in it, too. How did they get here? How did this evolve?' (PC5)

Fourth, regarding **cultural skills** employees mentioned that they were able to address and inform clients more qualitatively (by having an informal talk on the street), to develop a capacity to care for older people with a migration background (by respecting individual preferences) and to work on a relationship of trust (by being close and accessible to make people feel comfortable). As a CHW explained:

'In the first contact with the person, it's important to make them feel comfortable, to give them some confidence, because it's all new. Like the person yesterday, I gave her my phone number if she wanted to phone to see if her husband was okay. It's little things like that to put the person at ease. It's normal, she doesn't know me, she doesn't know how I'm going to manage with her husband. Afterwards, she gave me a big hug.' (CHW 3)

Fifth, different examples of **cultural proficiency** were found inductively. The examples given by the participants can be divided into two levels: surface structure and deep structure. Surface structure is about adapting practice to immediately observable behavioural and social characteristics of the target group (Resnicow et al., 1999). Examples given by the participants included adapting leaflets, using representative images, and including Halal cooking. However, across the focus groups, it was clear that outcomes at the level of deep structure were more difficult to accomplish. Deep structure concerns the inclusion of social, cultural, environmental, psychological and historical characteristics that influence the behaviour of the target group in the development and adjustment of the care offer and organisation (Mier et al., 2010; Resnicow et al., 1999); in changes to deep structure, the care provision and how it is organised would be adapted to the target group, not the other way around. A CHW explained the importance of considering customs and traditions within providing care and understanding where these were coming from:

"When you go to a Moroccan family, you know: "I have to wait a bit before I go in." Or you have to ask, "How does that happen with you?" "What do I have to do?" "What don't you like?" "What do you like?" Because we Moroccan families don't open up immediately, the women first put on a headscarf. But in the place of the physiotherapist, I would think: "Oh, they're not at home."" (CHW7)

Some ideas raised by the participants to implement in the future were employing go-to persons for cultural competent care and working in culturally diverse teams.

Last, dynamicity took place mostly with the direct participants of the training events. Participants indicated they felt more confident after taking part in the training. During the internships and field visits, the CHWs interacted with older adults and got to know them, their living environment, struggles and enjoyments. A CHW explained how the activities in the field taught her more then only the theory could:

'There's the theory, but we've really been in the field. We've met older people, we've done interviews, we've made visits and all that, so we've really seen the obstacles and the problems, in fact, there's the culture, the traditions, in the field we learn a lot.' (CHW7)

Overall the respondents noted little overspill to the home care organisations in terms of cultural competences. However one case was seen where overspill to the whole home care workforce was realised. This CHW testified she felt included in the particular home care organisation as a 'full' colleague from the outset. In that case, the scope of the outcomes was broader, as colleagues at the management level were taking concrete steps toward culturally competent care (i.e. adapting leaflets and offering culturally sensitive training). In other home care organisations the CHW was often only seen by colleagues as an intern and therefore not completely integrated into the team. These home care organisations noted fewer changes in the cultural competences of their employees. This showed the importance of having the whole team on board in order to be able to take concrete steps.

# 3.2 | MECHANISMS

The analyses of the mechanisms demonstrated the importance of strengths-based education (Lopez & Louis, 2009), consisting of five principles: (1) measuring students' strengths, (2) individualising the learning experience, (3) networking for praise and recognition, (4) deliberately applying strengths within and outside classroom and (5) intentionally developing strengths through novel experiences.

# 3.2.1 MEASURING STUDENTS' STRENGTHS

The strengths of the CHWs were explicitly measured at the start of the training programme. Two strengths in particular were engaged actively in the initial interview and classes: (1) migration background and (2) previous experience or interest in care.

First, the CHWs had diverse migration backgrounds, and the trainers explicitly asked for their perspectives as input in their classes. The mix of cultures among the CHWs was perceived as essential for achieving cultural competence:

'It's a nice mix, there's all countries, each with its own tradition, each with its own culture, each with its own philosophy, I personally like the mix.' (CHW5).

Second, previous experience or interest in care were seen as assets in following the training. Participants were able to appeal to their existing knowledge and previous experiences during the training and draw on that experience in reflecting on norms and values.

#### 3.2.2 INDIVIDUALISING THE LEARNING EXPERIENCE

To individualise the learning experience, the training was tailored to the students' experiences and strengths in four ways: (1) engaging their knowledge and experiences and highlighting strengths, (2) sharing practical examples about care among different cultures, (3) taking into account their life stories and motivation and (4) the project coordinator providing learning support.

First, trainers actively engaged the knowledge and experiences of the CHWs and highlighted their strengths to encourage an open attitude and look for solutions together. Second, in class the participants were able to give practical examples of care among different cultures from their own experience. Third, trainers found that using digital stories in class was a way of ensuring that the life stories and motivations of the participants were taken into consideration. Digital stories are often used in training for health or social work to work on emancipation by giving people a voice in telling their personal story (Vacchelli & Peyrefitte, 2018). Fourth, monthly meetings between the participants and the project coordinator were organised; the CHWs explained how this strengthened the group process and provided learning support (e.g. discussion of the learning path, work experiences and homework assignments). Support throughout the training was crucial, according to project coordinators:

'So that the participants are not sent out onto the streets at random to do their assignments. No, there's the training, that those people are formed step by step in that direction.' (PC1)

## 3.2.3 NETWORKING FOR PRAISE AND RECOGNITION

Networking among CHWs was encouraged in order to share information and bring talents together through three activities: (1) discovering one's own network, (2) learning methods to broaden the network and (3) sharing knowledge and experiences with care employees.

First, participants discovered their own network during the courses, after which they learned methods for broadening that network. Because of the knowledge they had acquired of the care system, some CHWs occupied a stronger position in their social network:

'It's true that we learnt a lot [...], there are a lot of things that I passed on to those around me and they were very happy that they got to know it. And I was so happy because I knew something good, so I passed it on every time there was someone in need, I said, "This is what I learned today." (CHW7)

Then, the CHWs identified the importance of sharing knowledge and experiences with care employees during the formally organised exchange moments. These were organised twice and brought together the CHWs and care employees to share their experience and reflect on how to work in more culturally competent ways. One care employee explained how she learned from the CHW in her organisation:

'The CHWs in our organisation have followed a class and they will come to you. You talk about certain things [...] and then they already have a certain opinion. At that moment it is also a learning moment for me. It really is a win-win situation because of the visits they have made as part of their training. They also got to know different organisations that they didn't know about before, and through them I learned that too.' (CE3)

3.2.4 DELIBERATELY APPLYING STRENGTHS WITHIN AND OUTSIDE THE CLASSROOM

Participants were encouraged to gain more knowledge by applying their strengths outside the classroom in two ways: (1) take-home assignments and (2) spontaneous work as CHWs.

First, the CHWs noted that their take-home assignments helped them to understand the needs of older people better:

'Because I start to understand, I go to the interview [as part of the assignment] and look up about residential care centres and some organisations and talk with them about the culture, listening to them.' (CHW3)

Second, some participants gained enough confidence to work spontaneously as CHWs in their community, informing older people and their families about the care offer:

'It went so far that the CHWs themselves spoke to the older people about "I see you're having a hard time, but you know there's a service centre around here, don't you?" And they themselves were very happy that they could communicate that.' (T1)

3.2.5 INTENTIONALLY DEVELOPING STRENGTHS THROUGH NOVEL EXPERIENCES

Novel experiences developed the CHWs' skills and knowledge through (1) field visits and (2) internships.

First, participants valued the field visits, which allowed them to get to know the care services and broaden their views on care. After all, in the beginning of the training CHWs had some prejudices towards care services. During the training many encounters allowed the CHWs to talk with clients and care employees, discussing with them the needs, which made them have a more positive attitude towards healthcare services:

'They have started to look at differently and they have started to realise that it is okay to have care provided by professionals.' (T1)

Second, by being involved as interns in the home care organisations, CHWs gained extensive knowledge and developed self-confidence in their work. In this role, care employees observed that the participants were loyal to the home care organisations and proud to be part of them: 'She was also very proud to be involved in this project, to represent our organisation in this way. I feel an enormous loyalty with her.' (CE6)

Similarly, the project coordinators were convinced that the CHWs had brought new perspectives to the home care organisation:

'I think that we were subconsciously already doing something about culturally competent care, but maybe not enough, and now it lives on different levels and within different services.' (PC1)

# 3.3 | CONTEXT

The context that defined the achievement of culturally competent home care organisations by influencing the mechanisms was structured according to Bronfenbrenner's ecological model (1979). In this study, the (1) micro-, (2) exo- and (3) macro-levels will be described.

First, at the micro-level respondents found that their interest in care and its cultural aspects shaped their attitude during the training, as did the fact that they had relevant competences in care and unique cultural experiences:

'Because, when I was a child I wanted to be a nurse, to care for the people. Different cultures, different ages, that is not a problem. So it is something inside me. You cannot ask anyone to do that job, you have to be really motivated.' (CHW3)

Second, at the exo-level the specific job of CHWs, as developed in this project, was not yet a recognised profession. Consequently, having no tangible workplaces after the internships for CHWs limited the home care organisations to include the participants in their organisation afterwards and with that limited the transfer of cultural competences from the CHWs to other employees. Additionally, the extent to which the home care organisation was able to be flexible in offering opportunities for the CHWs during the internship to participate actively in the organisation also determined the context. A project coordinator noted that home care organisations could offer even more opportunities in the future:

'[...] bring the CHWs on board, all in the positive sense, that they would bring that expertise into the operation of the home care organisation.' (PC5)

Last, at the macro-level the political support defined the actions that could be taken:

'If we can't adjust our own offer, we'll have to tell our minister. He sees that this target group will not be reached, but then we have to learn a number of lessons from this study: to show what is wrong with the offer in Brussels to approach this target group and with our staff training package.' (PC2)

The support of the management of the home care organisation was also a factor, as this reflected the capacity of the project and determined which options could be put into practice:

'That's a classic thing, expectations around interculturalism. So, diversity experts are always recruited all over the organisation to increase income, but yes, there is something in return. Namely, interculturalising processes in which the policy also has to be implemented by the organisation itself.' (T2)

# 3.4 | WHAT WORKS IN WHICH CONTEXT? BRINGING TOGETHER CONTEXTS, MECHANISMS AND OUTCOMES

Although the contextual factors outlined above defined important preconditions for the mechanisms described, one of these turned out to have a particularly important impact on the outcomes: high participation of CHWs in home care organisations. The degree to which the home care organisations offered opportunities for the CHWs to participate actively in the organisation could differ. This high participation was especially important because of three reasons. First, in the exchange between the CHWs and the home care organisations, mutual learning took place; this was very strong in some organisations, but not strong enough in others. As a result, what the CHW had learned could not be put fully into practice in the workplace, limiting the extent of the transfer to the entire organisation.

Second, to encourage this mutual learning, the CHW had first to be in a position to acquire ideas and knowledge about how home care organisations work; that is, the CHW had to have access to the everyday functioning of the organisation and sufficient support to make use of that access. One participant was especially strengthened in her role as CHW through opportunities to participate actively in meetings at the home care organisation:

'I had twice a week the meeting with her for how the work is, how the area is, how the training is, what it requires, the difficulties with the client, so I was well supported in fact.' (R1)

Third, CHWs were able to strengthen and stimulate the whole team by pointing out shortcomings in the services of the home care organisations:

'The highlight for me was when the two CHWs introduced themselves in a team meeting and then I heard afterwards from my colleagues that they knew what they were talking about, that they really learned things in the trainings and that it was actually very interesting for the colleagues.' (CE1)

#### 4 DISCUSSION

This study has investigated the outcomes, mechanisms and context of a work training programme for CHWs with the aim of creating culturally competent home care organisations.

Although the outcomes can be categorised according to different principles (Sharifi et al., 2019), the biggest impact of the project was the shift in mindset towards working in ways that are culturally competent. In this respect, the home care organisations involved in the project were encouraged to take specific steps for the future. However, it appears that, in most of the organisations, cultural competence was achieved only by the employees who were directly involved in the project through training. There was little overspill into the organisation more broadly. Previous research has highlighted the importance of providing cultural competence training to all employees and at different levels of care organisations (Kaihlanen et al., 2019; McCalman et al., 2017). Furthermore, only the surface structure of the organisations was addressed. The challenge remains of reorganising the deep structure to meet the needs of older adults with a migration background. As discussed in previous studies (Gebru & Willman, 2010; Kardong-Edgren & Campinha-Bacote, 2008), cultural competence is a process that develops in practice over time, and this helps to explain why changes to deep structure take longer than changes to surface structure.

Regarding the mechanisms, strengths-based education (Lopez & Louis, 2009) proved capable of engaging and empowering the participants. Three further principles crucial for education were

identified in the data. (1) Experience-based education (Kolb, 1984) puts the experiences of participants at the centre of training while also providing opportunities for reflection; here, this took place in the classroom, as well as in the field visits and internships. (2) Culture-based education (Singh & Espinoza-Herold, 2014) respects diverse knowledge systems and skills; here, the training was able to draw on the diverse backgrounds of the participants to create openness and respect for different cultures. (3) Group-based education (Roy & Lin, 1993) values group interaction; here, it was particularly useful in creating a safe learning space and increasing the motivation of the participants.

In terms of context, a key finding was the importance of the exo-level in creating opportunities for CHWs to participate actively in the home care organisation. This is in line with the findings of previous research (van der Hem-Stokroos et al., 2003). Therefore, strong commitment is required from home care organisations for mutual learning to take place and for cultural competence to be achieved in the organisation more broadly.

In the course of conducting this research, some limitations became apparent. First, the attribution paradox (Marchal et al., 2010) was in play, as might be expected in a realist evaluation of a complex project. The behaviour of participants and organisations is determined by many interlinked factors, and it may be impossible to assess the exact contributions of certain mechanisms or contexts to particular outcomes. Nevertheless, the value of a realist evaluation in providing a detailed picture of multiple determinants, and in categorising them as mechanisms or context, remains.

Second, the CMO configuration dilemma (Marchal et al., 2010) should be taken into account. In particular, the generative causal relationships between the outcomes, mechanisms and context need to be assessed, questioning whether the outcomes are the result of the mechanisms or whether the outcomes are better explained by contextual factors. Similarly, contextual factors may moderate the relation between mechanisms and outcomes, or an outcome may influence its context. Moreover, some contextual factors are essential for the outcomes, leading to confusion as to whether those factors form part of the mechanisms.

Third, it should be noted that the research design and time constraints in this study permitted only short-term outcomes to be measured. (It was necessary for the funding agency to receive an evaluation in a short time.) It is anticipated that additional outcomes would have emerged if the interviews had been conducted over a longer period. Nevertheless, the relatively short time frame for this study made it possible to draw rapid conclusions that can inform future projects.

However, some strengths could also be mentioned about this research. First, the research takes into account the different stakeholders at play in the project. Including this broad range of participants such as, CHWs, care employees, trainers and project coordinators, enabled the researchers to understand the multiple perspectives on the project.

Second, this research provides an overview of the context, mechanisms and outcomes. Not all research applying the CMO-framework gives an overview of all three (e.g. Mitchell, 2015), however we found it essential to give an overview of the context, mechanisms and outcomes to get a clear insight into the project.

On the basis of the findings of this study, a number of recommendations can be made for policy and practice regarding outcomes, mechanisms and context. First, in terms of outcomes, the focus on culturally competent care should be reflected upon in light of increasing attention to the question of person-centred care versus culturally competent care (Campinha-Bacote, 2011). Kaihlanen et al. (2019) have already probed whether this focus will lead to stereotyping and to individual differences between people of similar backgrounds being ignored. However, these concerns apply mostly to the early literature on cultural competence, which typically used a categorical approach; more recent work has focused on communication skills, awareness of cross-cutting cultural and social issues, and health beliefs present in all cultures (Epner & Baile, 2012). Culturally competent care has thus moved beyond assumptions about older people based on their cultural backgrounds and now aims to implement principles of patient-centred care (Teal & Street, 2009). In the work training programme in the present study, extra attention was paid to the diverse backgrounds of the participants themselves and their communication skills. As these aspects turned out to be a crucial element in culturally competent care, it is recommended that a patient-centred approach be included in programmes that aim to create culturally competent care.

Second, in relation to mechanisms, strengths-based education proved to be the basic principle of the work training programme. This ensured an approach based on the competences of the jobseekers with a migration background. All too often, such competences go unrecognised and underutilised (Schuster et al., 2013), despite their potential high value. Therefore, more training should apply the strengths-based approach to recognise and develop the strengths of individuals who might otherwise be perceived as underskilled.

Third, in terms of context, the active involvement, engagement and commitment of home care organisations is crucial to the creation of cultural competence. In order for the organisation to be able to benefit from their knowledge, CHWs should be actively involved (van der Hem-Stokroos et al., 2003). The creation of a fully supportive context requires investment in cultural competence for a whole organisation, not only some of its employees. Different levels of the care organisation should be addressed (Kaihlanen et al., 2019; McCalman et al., 2017) by developing a culturally competent strategy towards attitudes in the workplace.

# CHAPTER 7. DISCUSSION

# CHAPTER 7. DISCUSSION

This chapter presents the general discussion of the dissertation. Section 1 gives an overview of the main findings in relation to the research goals. Section 2 details the implications for policy and practice. Section 3 presents critical reflections and suggestions for future research. The chapter ends with the general conclusion.

# 1 | DISCUSSION OF THE MAIN FINDINGS IN RELATION TO THE RESEARCH GOALS

Universal access to care, defined as the absence of sociocultural, organisational, economic, geographical and gender-related barriers in care (Evans et al., 2013), is put forward by the World Health Organization as an overarching goal for health in its post-2015 development agenda. The United Nations member states underlined this goal by signing the Sustainable Development Goals, including achieving universal health coverage by 2030, and more specifically access to essential quality care services (World Health Organization, 2018).

However, so far universal access to care services is not yet realised for all older adults. The care individuals receive is determined by their demographic, social and economic characteristics, as well as by the characteristics of the environment (Levesque et al., 2013). This indicates that access to care might be restricted due to structural (i.e. funding and delivery of care services), contextual (physical, political, economic or social environment) and/or individual barriers (behaviour of providers and users) (Gil-González et al., 2015; Levesque et al., 2013). Adjoining this, service providers also find it complex to adapt their services to the needs of diverse older populations (Phillimore et al., 2019).

As a reaction to the lack of access to traditional formal care services, older people call on care from different places, using knowledge of various care practices and transnational networks (Phillimore et al., 2019). This dissertation looks at two such alternative care services provided outside the classical care offering. First, live-in migrant carers are employed to work in private households to meet the needs of domiciliary support and care (Horn et al., 2019). Second, community health workers are employed in care organisations to facilitate access to care services and contact people in the community who are not always reached (Shommu et al., 2016).

The overall aim of this dissertation was to explore alternative approaches (i.e. live-in migrant carers, community health workers) to organising care for older adults whose care needs are currently not met by formal care services. Three sub-aims were formulated:

- 1. To explore the potential of alternative care workers in addressing older adults' unmet care needs
- 2. To explore how alternative care workers can be empowered to better address diverse care needs of older adults
- 3. To explore how care organisations can be empowered to better address diverse care needs of older adults

The discussion of these three aims brings together insights of the four studies, as presented in *Chapters 3 to 6.* While the two alternative care approaches differ in aspects like training, formality and employment conditions, overarching findings can be formulated to answer the research goals.

# 1.1 | EXPLORING THE POTENTIAL OF ALTERNATIVE CARE WORKERS IN ADDRESSING OLDER ADULTS' UNMET CARE NEEDS

To understand the potential of alternative care services, the theory of access by Penchansky and Thomas (1981), as validated and adapted to the Belgian context by Fret et al. (2019), can be used to provide deeper insights into understanding the findings of the different chapters. The theory conceptualises different dimensions of access (i.e. the 7 A's) to analyse the fit between characteristics of care service providers and characteristics and expectations of users: affordability, availability, accessibility, adequacy, acceptability (Penchansky & Thomas, 1981), awareness (later added by Saurman (2016)) and ageism (later added by Fret et al. (2019)). Building on the findings of *Chapters 3 and 6*, we can conclude that community health workers and live-in migrant care workers both have the potential of increasing acceptability of care services. Live-in migrant carers add the potential of adequacy, while community health workers add the potential of awareness. These three dimensions will be discussed below.

First, both live-in migrant carers and community health workers increase the *acceptability* of care (i.e. whether older adults are comfortable with the characteristics of the care service (Penchansky & Thomas, 1981).

Based on the findings of *Chapter 3*, we can state that live-in migrant carers increase acceptability of care by providing person-centred and continuous care. The personal approach to care is highly valued by older adults, since the live-in carer can align the care to the older adult's daily life. This makes it possible to build a relationship of trust, whereby the specific needs of the older adult are taken into account by the live-in carer. Older adults appreciate being cared for by one and the same person rather than by different actors, which is often the case with formal care services. Such personnel continuity in home care is also valued in other research, as it may reduce hospitalisation, increase functioning in daily activities (Russell et al., 2011), and make the older adult feel calmer and more balanced (Horn et al., 2019). The findings of *Chapter 3* show that high potential lies in this care arrangement because people feel they have a voice in it and retain mastery over their lives. It furthermore demonstrates that preferences of older adults concerning care play a role, as confirmed in previous studies that stress the often-negative associations with residential care homes (Halperin, 2019; Horn et al., 2019). This makes the care by a live-in carer, who provides care at home for some older adults, more acceptable and preferred to the alternative of a nursing home.

Community health workers show the importance of taking into account cultural preferences for the acceptability of care. Research has called for more culturally competent care services in improving access to care (Hemberg, 2019; Henderson et al., 2018). As described in *Chapter 6*, one of the outcomes of the community health worker-programme was the increase in cultural competence of the care services, a lower threshold for migrant families to the care organisation, and an increased acceptability of traditional care for a diverse group of older adults. In the Brussels project (*Chapter 6*), community health workers realised the six attributes of the cultural competence model of Sharifi et al. (2019): increased cultural awareness, cultural knowledge, cultural sensitivity, cultural skills, cultural proficiency and dynamicity. Community health workers are strongly committed to increase the extent to which older people feel comfortable with the presence of the care provider and thus boost the acceptability of care services (i.e. home care and care in the community). A second potential lies in the way alternative care workers contribute to the *adequacy* dimension (the extent to which care organisations operate practically in ways that meet the preferences of older adults). This research shows that the particular presence of live-in carers, especially because of their 24-hour presence, contributes to adequate care. *Chapter 3* demonstrates that older adults employ live-in migrant care workers because they want to age in their familiar place and thus delay the move towards residential care. According to older adults and health professionals, the need for 24-hour care cannot be met by formal care services. When older adults want to obtain the support they need from formal care services, they have to call on different care services for different tasks, organising their lives around the schedules of the care professionals. The permanent presence of the same live-in carer responds to these concerns and ensures that older adults retain control over their lives. Pacolet and De Wispelaere (2018) confirm the often-fragmented care of formal care services in Belgium, explaining this by the division of the organisational landscape of care services between the Federal government (responsible for medical care) and the communities (responsible for non-medical care).

Third, alternative care workers have the potential to increase *awareness* of care services, which has been found especially in our studies on community health workers. Awareness is defined as providing effective communication and information with relevant users (Saurman, 2016). Despite the need for care, older people with a migration background make almost no use of home care services and formal home care services do not reach them sufficiently. There are various reasons for this, including a lack of clear information and knowledge about appropriate routes to get access to care (Suurmond et al., 2016). As also shown in previous research, the presence of community health workers can increase the health utilisation of community members (Andrews et al., 2004; Swider, 2002). Findings from *Chapter 6* demonstrate that community health workers do this by creating awareness of the existence and functioning of care services, by communicating effectively and by implementing targeted information strategies. For example, the community health workers of the Brussels project developed cultural skills that enable them to address and inform older adults in a more qualitative way, and to work on a relationship of trust. Consequently, older adults are better informed and find access to care services.

The different dimensions of access to care services are intertwined (Fret et al., 2019; Levesque et al., 2013), also in the cases of live-in migrant carers and community health workers – especially acceptability and adequacy; acceptability and awareness are strongly intertwined and can reinforce one another (see *Chapters 3 and 6*). For instance, live-in migrant carers increase the adequacy of care services, meaning they operate in ways that meet the preferences of older adults, by being present 24/7. At the same time, this reinforces the acceptability, meaning older adults feel comfortable with the care provided, as one single person is providing the care and a more personal approach can be assured. When community health workers increase awareness of care services, which entails that relevant information reaches older adults in need of care, the acceptability of care services is reinforced too. Older adults will know better what to expect and how care will be provided.

# 1.2 | EXPLORING HOW ALTERNATIVE CARE WORKERS CAN BE EMPOWERED TO ADDRESS DIVERSE CARE NEEDS OF OLDER ADULTS

Van Regenmortel (2002, p. 76) defines empowerment as "a process of amplification through which individuals, organisations and communities gain control over their own situations and their environments and do so through gaining control, sharpening critical consciousness and encouraging participation". Throughout the different chapters of this dissertation, empowerment is seen in an amplification and growth process that is experienced by the alternative care workers. **Chapter 3**, for example, demonstrates the growth process of live-in migrant carers through their personal and social changes experienced as a result of their migration and work. These changes occur at different phases of their lives, such as in their role as parent, their relationship with partner and family, and their external and self-recognition. In **Chapter 5** community health workers mention that because of the work-training programme their knowledge, social skills and attitudes have increased, their employability is facilitated, their social network is enlarged, and they have gained social recognition.

And so live-in migrant carers experience growth and change through personal life choices and individual struggles. Community health workers are mainly empowered through the work-training programme. Notwithstanding these different trajectories, the findings reveal some generic elements that can contribute to empowering alternative care workers. First, peer learning and peer support, and recognition are found to be crucial for both live-in migrant carers and community health workers. Other unique elements are found to contribute too, such as mentoring and experience-based learning, as these were explicitly included in the work-training programme. In this section, we will focus on the communal factors for alternative care workers' empowerment: peer learning and peer support, and recognition.

#### 1.2.1 PEER LEARNING AND PEER SUPPORT

Alternative care workers can be empowered through peer learning and peer support to better address diverse care needs of older adults. This peer learning and peer support can take place in both *formal and informal settings*. *Chapter 5* demonstrates that peer learning and peer support can take place formally in class when time and space is provided to share experiences and thus when there are also instructions in the form of a class assignment, as well as through informal contacts between community health workers after class. *Group-based learning*, in which group interaction is valued and encouraged during the training (Roy & Lin, 1993), creates a safe learning space and increases the motivation for learning *(Chapter 6)*. Additionally, community health workers in the training were sharing practical examples and each person would bring in another insight based on their background and experience. They were encouraged by the trainers to have an open attitude and look together for solutions to case studies.

Although literature already highlighted that live-in migrant carers can count less on peer support than care workers who are employed in residential settings, because they often work alone in private homes (Turnpenny & Hussein, 2021), *Chapter 4* demonstrates that peer support is indispensable for live-in migrant carers: they are looking for other migrant workers from the same country through social media and employment agencies to meet in Belgium. Having the same experiences with working and living conditions creates bonds of solidarity and perseverance between them as live-in carers. This especially helps cope with emotionally challenging elements of live-in care. Previous literature also highlighted that peer support can help carers cope with experiences of racism at work, by e.g. vocalising their rights to employers (Scrinzi, 2019; Shutes & Walsh, 2012; Stevens et al., 2012). The findings of *Chapter 4* further show the difficulty of building a social network in the host country, because of limited free time, short stay in the host country, etc. This incentivizes most live-in migrant carers to also look for transnational support from close family and friends who are still living in the home country. Previous literature likewise evidences that having regular contact with family and friends may relieve psychological stressors (de la Cuesta-Benjumea et al., 2011; van Bochove & zur Kleinsmiede, 2021). Social support is used by live-in migrant carers as a coping and perseverance strategy for what can be extremely difficult working and living conditions.

#### 1.2.2 RECOGNITION OF ALTERNATIVE CARE WORKERS

The findings demonstrate that experiencing recognition contributes to the empowerment of alternative care workers in addressing older adults' diverse care needs. The various studies included in this dissertation specify that recognition can manifest as: 1) recognition of the profession; 2) societal recognition; 3) recognition of experience, knowledge and skills. These three aspects will be discussed for live-in migrant care workers and for community health workers.

1) Findings of *Chapters 3 and 4* point out that live-in migrant care workers can be empowered through recognition of their profession. While their work is getting wider attention and is more recognised at the European level (i.e. EESC, 2016; EESC, 2018), this is not yet translated into policies recognising and protecting the rights of live-in migrant carers in Belgium and many other European countries. This is much needed, as *Chapter 3* reveals that several critical questions were raised by older adults and their families employing live-in migrant care workers in terms of their training, employment conditions and legal status. In *Chapter 4*, live-in migrant carers themselves point out the lack of a written contract across the board, vagueness of the terms of employment, violations of free time, etc. Furthermore, the International Labour Office (ILO) addresses the importance of fair working conditions for both care worker as care receiver: "Care recipients and care workers share a 'common interest' in finding socially optimal care arrangements that maintain the quality of care, its suitability with the needs of workers with care responsibilities as well as respect for care workers' rights" (King-Dejardin, 2019, p. 2). Building on the findings from *Chapters 3 and 4*, we can conclude that the often precarious migrant status, isolation from organisational sources of support and lack of information for both parties contribute to poor working conditions and uncertainty about the quality of care. This is supported by previous literature which argues that good-quality care should be seen through the perspectives of both care receiver and caregiver (Daly, 2001), where standards of care services, relationships involving caregiving, contractual arrangements and working conditions are taken into account (King-Dejardin, 2019).

Additionally, as indicated in *Chapter 6*, the specific job of community health workers as defined in the Brussels project is not yet a recognised profession. The lack of a legal framework for the profession limits formal care organisations in permanently integrating community health workers structurally. Despite the trainings provided to community health workers, despite the realised added value of their work, in the wider debate in the literature discussion remains about the professional status of community health workers. Currently, as also proven in other studies, community health workers are being deployed either as formally paid professionals or as volunteers (Delgado, 2020) who sometimes go unrecognised and therefore unsupported, and thus often work in non-traditional settings that seem to exist as an invisible parallel care system (Leon et al., 2015). Professional recognition is crucial in the empowerment, as professional status also serves as a gatekeeping function. Rules, regulations, credentialing and responsibilities are attached to the status, which can restrict practice but also benefit instrumental rewards (such as access to training or a physical working location). Participants (care employees, project coordinators, community health workers) underlined in the interviews that the function of community health workers should be created within care organisations. Supporting projects in which community health workers work as volunteers will not be sufficient to empower care workers in a sustainable way. In addition, the access to trainings should be low treshold. The community health worker trainees in the Brussels projects could access the training based on their previous care experiences or based on diplomas that are currently not recognised in Belgium. Besides, the training was easily accessible in terms of language requirements.

2) Societal recognition can empower alternative care workers. The findings of *Chapter 4* demonstrate that feeling recognised by their social environment is not self-evident for all live-in migrant care workers. This lack of recognition often stems from negative connotations attached to providing live-in care, such as having a low-paid job or performing domestic work. Experiencing more social recognition, such as acknowledging that they often financially support their families from a distance or more appreciation from the relatives of the older person they provide care for, can help live-in carers feel proud of their work and feel recognised by those around them. Findings from our studies confirm the conclusions of Peterson (2018) on the struggles with recognition of domestic work globally (i.e. recognising it as work and as decent) and the undervaluation of care (i.e. defining care as work, rather than seeing unpaid care as women's responsibility).

*Chapter 5* shows how community health workers highly value the societal recognition they receive for their work from community members. They felt recognised as key figure in the neighbourhood who people easily contact for questions and help. This societal recognition is part of the increased social capital they experienced after following the work-training programme, and can empower them to enact change and advance their position while also providing opportunities to improve community members' health (Saint Onge & Brooks, 2021).

3) Recognition of knowledge and skills can contribute to the empowerment of alternative care workers. In the first place, the majority of live-in migrant care workers involved in our studies did not follow a formal nursing or home care education (*Chapters 3 and 4*). However, participants (care receivers, employment agencies and formal care professionals) believe that live-in migrant care workers acquired the necessary skills to provide live-in care through previous care experiences with family members or personal qualities and characteristics (like being committed or cheerful). This perception can also be clouded by the fact that women are generally perceived as natural caregivers (King-Dejardin, 2019; Scrinzi, 2019). Particularly because caregiving is perceived as natural, the skills that are necessary for caregiving work are not highly valued by society and by consequence detract from the professional status of live-in carers (Scrinzi, 2019).

In addition, *Chapter 6* demonstrates that the knowledge and skills of community health worker trainees are recognised through applying strengths-based education (Lopez & Louis, 2009) in the work-training programme. In this way, their competences and strengths can be identified, recognised, affirmed and amplified. All too often, skills of jobseekers go unrecognised and underutilised (Schuster et al., 2013), and they are perceived as underskilled despite their potential high value for the job. Strengths-based education is applied in the Brussels project through the following educational principles (as pointed out in *Chapter 6*): 1) measuring students' strengths: taking into account the

diverse background and previous experiences of community health worker trainees; 2) individualising the learning experience: engaging knowledge and experiences of community health worker trainees; 3) networking for praise and recognition: discovering the own network and learning methods to broaden the network, sharing experiences with care employees; 4) deliberately applying strengths within and outside classroom: performing take-home assignments and spontaneous work as community health worker; and 5) intentionally developing strengths through novel experiences: doing field visits and internships.

# 1.3 | EXPLORING HOW CARE ORGANISATIONS CAN BE EMPOWERED TO ADDRESS DIVERSE CARE NEEDS OF OLDER ADULTS

The empowerment of care organisations to better address the diverse care needs of older adults can be accomplished by mutual learning between alternative care workers and employees of traditional care organisations, and by learning from shortcomings in the care offering of the organisation. As community health workers work more with, within and for care organisations, our emphasis will be on *Chapters 5 and 6.* However, also *Chapters 3 and 4* on live-in migrant carers provide some insights into the empowerment of care organisations to address diverse care needs; this will be discussed below.

# 1.3.1 MUTUAL LEARNING BETWEEN ALTERNATIVE CARE WORKERS AND EMPLOYEES OF TRADITIONAL CARE ORGANISATIONS

To ensure that care organisations can be empowered by employing community health workers, *Chapter 6* demonstrates that mutual learning between community health workers and care employees must be enabled. Mutual learning entails that both community health workers and care employees in care organisations exchange knowledge, ideas and experiences and learn from each other. Mutual learning asks for strong commitment and engagement from care organisations. In order to enable mutual learning, a fully supportive context should be created. This requires investment in cultural competence for the entire organisation, at different levels of the organisation and not only for some of its often-lower-level employees. This finding is also supported by previous literature by Kaihlanen et al. (2019) who studied nurses' perceptions about the content and utility of cultural competence training. To this end, *Chapter 6* points out that creating opportunities for community health workers to participate actively in the care organisation is essential, otherwise the transfer of knowledge from the worker to the entire organisation will be limited. The Brussels project shows that the extent of active involvement of community health workers in care organisations differed depending on how flexible a care organisation was in offering opportunities to integrate these workers into their daily operations. It appears that, in most of the organisations, cultural competence is achieved only by those employees who are directly involved in the project through training, with too little overspill into the organisation more broadly.

*Chapter 5* additionally highlights community health workers' need for mentoring, in which both the internship mentor (often a care employer) and the community health worker trainee can share experiences and learn from each other. Care organisations can play an important role in mentoring. In the Brussels project both 'mentoring as befriending' and 'mentoring as coaching', as described by Pawson (2006), showed to be effective. Mentoring as befriending implies creating trust and sharing

experiences. Mentoring as coaching entails stimulating trainees to go beyond their limits and encouraging them to learn new skills.

#### 1.3.2 LEARNING FROM SHORTCOMINGS IN CARE OFFERINGS

By learning from shortcomings in their care offering, care organisations can be empowered to address diverse care needs and adapt the deep structure of their organisation. In addressing the motivations of older adults and their families to hire live-in migrant care workers, *Chapter 3* reveals shortcomings in the formal care offering. Formal services tend to be either insufficient for older adults to be able to age in place (e.g. lack of round-the-clock care guarantee) or do not meet their needs and preferences. In their motivations, older adults express that they are looking for care services that enable them to preserve mastery over their life and care process, in which they feel a cultural connection, and where person-centred and continuous care is guaranteed. Care organisations could learn from these motivations by adapting their services to the needs expressed by older adults (e.g. enabling them to stay in control when receiving care and providing culturally competent, person-centred and continuous care).

*Chapter 6* indicates that active involvement of community health workers can identify shortcomings in the offerings of care organisations and motivate them to perform more culturally competent work. However, it remains difficult to accomplish a change on the deep structure of a care organisation, as the care offering is developed and adjusted to the target group and not the other way around. In literature, deep structure is defined as the inclusion of social, cultural, environmental, psychological and historical characteristics that influence the behaviour of the target group in the development and adjustment of the care offering and organisation (Mier et al., 2010; Resnicow et al., 1999). As discussed in previous studies (Gebru & Willman, 2010; Kardong-Edgren & Campinha-Bacote, 2008), cultural competence is a process that develops in practice over time and therefore deep structural changes might take longer than superficial ones (e.g. adapting leaflets, using representative images). In order to enable mutual learning and change the deep structure, the organisation must be genuinely committed to change. This entails genuinely involving all levels of the organisation into working culturally competent and not only care employees who are in direct contact with older adults. Additionally, organisations must genuinely recognise community health workers' invaluable expertise and not using them to show their quick efforts in working culturally competent.

## 1.4 | OVERALL REFLECTION ON THE RESEARCH AIM

1.4.1 KEY CHARACTERISTICS OF LIVE-IN MIGRANT CARE WORKERS AND COMMUNITY HEALTH WORKERS The alternative care workers included in this dissertation, being live-in migrant care workers and community health workers, have important commonalities and differences. Based on our research, we will outline some key differences between both professions (see table 8).

The first difference can be seen in terms of their target group. Community health workers mostly address the people in their community, often people with a migration background who are experiencing certain barriers towards care services. Live-in migrant carers generally have wealthier clients, who are aware of the care services but do not find their preferences being met in the formal care offering.

Second, the nature of employment and consequently working conditions differ. Although in some countries there is discussion whether community health workers should be formally employed

or be volunteers (Delgado, 2020) the community health workers in the Brussels project are all employed by organisations through formal employment. Live-in migrant care workers on the other hand can be employed by agencies or by private persons, sometimes acting in a grey zone. This has important consequences for their employment conditions, which are often deficit for live-in migrant care workers.

Third, the community health workers in the Brussels project followed a work-training programme and sometimes had already educational degrees in the care sector which were not recognised in Belgium. Some live-in carers followed a short nursing course, others did not have any training related to care and were relying on their informal care experience.

In addition, both alternatives make access to care for older adults possible by working in the community. This locality is important. The community health workers do this by their outreach approach. They go to see people and not the other way around. They are pro-active. Live-in migrant carers enable older adults to stay at home and offer care in their home.

Both alternatives also make clear that care work has to be valued more, since they offer a significant contribution to care. However especially for live-in migrant care workers this includes economically valuing them, with a fair remuneration and complying to employment conditions. For community health workers, an important goal was the recognition for their profession and role by the care services: so that are fully integrated in care organisations and can participate actively.

| Live-in migrant care workers                 | Community health workers  |  |  |
|--|---|--|--|
| Broad range of clients, generally wealthier  | Often clients with migration background, people in the community        |  |  |
| Formal employment through agencies/ grey     | Formal employment in care organisations/                                |  |  |
| zone through private persons                 | volunteering  |  |  |
| Short training course/ no training on care   | No recognised educational degree/ previous experiences in informal care |  |  |
| Working in the community by offering care at | Working in the community by outreach                                    |  |  |
| home   | approach  |  |  |
| Recognition needed to comply to employment   | Recognition needed to participate actively in                           |  |  |
| conditions                                   | care organisation   |  |  |

TABLE 8 Key differences between live-in migrant care workers and community health workers

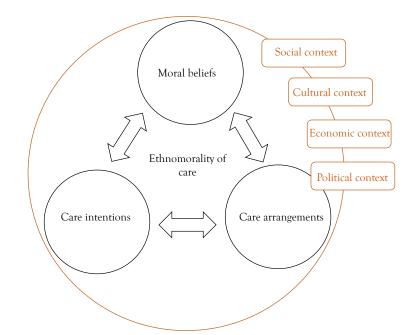


FIGURE 6 Ethnomorality of care model, supplemented by own findings

In the introduction of this dissertation, I used ethnomorality of care to conceptualise preferences towards providing and receiving care. While investigating the overall aim of this dissertation, 'to explore alternative approaches in organising care for older adults' unmet care needs', the concept of ethnomorality of care provided insights into caregivers' and care receivers' experience of care. This concept acknowledges the interplay between what people think is morally acceptable for care (moral beliefs), what they plan to do in the future (care intentions), and what they actually do to provide care (care arrangements). However, there is a gap where these three dimensions do not meet. This keeps older adults from the care they want to receive, and at the same time keeps care workers and care organisations from the care they want to provide. In order to provide quality care, this gap should be reduced as much as possible. Throughout the dissertation, my argument is that empowering care workers and care organisations can be a first step in reducing this gap.

Alternative care workers' potential in addressing older adults' unmet care needs lies in increasing acceptability, adequacy and awareness of care services. In addition, care workers can be empowered to better address older adults' care needs through peer learning and peer support, and through professional, societal, and knowledge-based recognition. Care organisations can likewise be empowered through mutual learning and learning from shortcomings in their care offerings.

Still, empowering at the individual level of the care workers or the mesolevel of the care organisation will not be enough to reduce the gap between the three dimensions (moral beliefs, care intentions and care arrangements). Care workers are active agents to a limited extent. They operate in certain structures over which they lack control. We therefore argue that ethnomorality of care takes place within certain boundaries set by structures (see Figure 6). As empowerment too is underpinned by the social, cultural, economic and political context (World Health Organization, 2022), this influences the experience of care and thus the ethnomorality of care. The following dimensions of context play a role in the ethnomorality of care:

- 1. The social context.
  - The valuation (or lack thereof) of care work defines who provides care and how care is provided.
  - The power relations that are experienced within a care situation determine how care is provided.
  - Language barriers define the social relations within a care relationship.
- 2. The cultural context.
  - Cultural preferences characterise the care at play.
- 3. The economic context.
  - The limits of informal care define which care is provided and by who. For instance, children who want to provide informal care but who are limited because of their working hours.
  - The care offerings of the public and private market define which care is available to call upon.
- 4. The *political* context.
  - The availability of formal employment and access to training defines who can provide care.
  - Policies in migration and work define who can work in Belgium as a carer, doing regular work and while being entitled to social security.

# 2 | IMPLICATIONS FOR POLICY AND PRACTICE

Based on the overall findings of this dissertation, this section provides implications for policy and practice. While we aim to formulate overarching implications concerning alternative care workers, some will still be more applicable to either live-in migrant care workers or community health workers. *Chapters 3 and 4* present specific implications for live-in migrant care workers, *Chapters 5 and 6* for community health workers.

## 2.1 | VALUE ALTERNATIVE CARE WORKERS ECONOMICALLY, SOCIALLY AND POLITICALLY

To meet current care needs, policymakers, care providers and older adults are struggling to recruit competent carers. Increasing numbers of care workers with a migration background are being recruited as an answer to this shortage (Colombo et al., 2011; Stone, 2016; Weicht, 2021). While *Chapter 3* highlights overall positive experiences of older adults with the care of, for instance, live-in migrant care workers, the overall findings of this dissertation demonstrate that the vital role of alternative care workers is not valued sufficiently – economically, socially or politically.

In relation to *economically valuing* alternative care workers, *Chapter 3* shows that live-in migrant care workers are paid less than their non-migrant counterparts. Community health workers too are often 'employed' as volunteers (Delgado, 2020). Fair remuneration should be a first concern for the valuation of alternative care workers, the more so because they are often economically responsible for their family, as evidenced in *Chapter 4*. This would contribute to Sustainable Development Goal target 8.5 on equal pay: "By 2030, achieve full and productive employment and decent work for all women and men, including for young people and persons with disabilities, and equal pay for work of equal value" (United Nations, 2015). Additionally, the need for increased societal valuation of care workers with a

migration background is reflected in the current low status attached to the work and perceptions of low-skilled workers.

First, community health workers may well feel social recognition from community members they can help (*Chapter 5*), and live-in migrant care workers may feel proud of performing their work because of the recognition of their family and the family of the older person (*Chapter 4*). And yet, their low societal status is demonstrated when we observe that not all community health workers are fully integrated into the care team (e.g. not allowed to participate in meetings) and are used to generate only superficial structural changes (*Chapter 6*). Also, live-in migrant care workers struggle with negative connotations attached to live-in care and are often expected to work round-the-clock, even if this violates their contract. The expectation to work more hours might stem from the undervaluation of care work and from asymmetrical power relations between older adults and live-in migrant care workers, where the latter have little bargaining power left (*Chapter 4*).

Second, regarding the perceptions of low-skilled workers, despite the findings of *Chapters 3 to 6* showing that alternative care workers often have an educational background or previous experience with care, they are regularly perceived and treated as low-skilled. In fact, care workers with a migration background tend to be overqualified (International Labour Organization, 2013). In the report 'Equal rights for migrant care workers', Wadehra (2021) argues that the consequence of being perceived as low-skilled is being underpaid in comparison to higher-skilled carers. Again, this also contributes to the low status (Fisher et al., 2021). As this care is most often offered by women, questioning the low status also challenges gendered ideologies on care. Counteracting this would also contribute to Sustainable Development Goal target 5.4 on recognising unpaid care and promoting shared responsibility within the household: "Recognize and value unpaid care and domestic work through the provision of public services, infrastructure and social protection policies and the promotion of shared responsibility within the family as nationally appropriate" (United Nations, 2015). Women are frequently perceived as natural caregivers, so the skills that are necessary for care work are not highly valued (Scrinzi, 2019). This contributes to the lack of training and recognition of previously acquired skills, as also highlighted in *Chapter 5*.

Third, alternative care workers should be politically valued, as political regulations can shape working and living conditions. Both Chapters 3 and 4 evidence differences in the experiences with working conditions of live-in migrant care workers who are employed by private households or agencies (e.g. salary, entitlement to holidays, social protection). Older adults should be required to employ live-in migrant care workers through formal channels, with registered contracts, following the Domestic Workers Convention (No. 189) of the International Labour Organization (International Labour Organization, 2011). As pointed out in *Chapter 3*, live-in migrant carers often lack a written contact or have no firm description of their role and tasks. This has consequences when appealing for sufficient rest during caregiving obligations (Heng et al., 2019). The migrant care sector should be regulated more strictly in order to increase formality, as other European countries have already done (e.g. Italy, France, the Netherlands) (Da Roit & van Bochove, 2017; King-Dejardin, 2019). In addition, a formal employment status is believed to reduce precariousness (Fisher et al., 2021). This would also contribute to Sustainable Development Goal target 8.8: "Protect labour rights and promote safe and secure working environments for all workers, including migrant workers, in particular women migrants, and those in precarious employment" (United Nations, 2015). As demonstrated in Chapter 4, an irregular status of live-in migrant care work comes with fewer opportunities for reporting labour right violations, not receiving a pension, limited access to healthcare, fear of deportation, etc. This formal employment status would also benefit community health workers in recognising their professional status and entitling them to institutional support and instrumental rewards (Delgado, 2020). Besides regulating the migrant care sector, these labour rights should also be enforced. Labour right inspections should ensure safe and secure working environments and stop excessive working hours. Inspections can contribute to Sustainable Development Goal target 5.2 on exploitation: *"Eliminate all forms of violence against all women and girls in the public and private spheres, including trafficking and sexual and other types of exploitation"* (United Nations, 2015). When migrant care is offered in the private home, it could be challenging to monitor labour rights (Fisher, 2021). *Chapter 4* shows that especially this setting can be an isolating experience for migrant carers, where social support is not always evident. Hence it is important to also include private homes in the labour inspections. To avoid putting workers at risk of deportation and push them even more into hidden work, labour inspections should operate separately from immigration procedures, as also suggested by Fisher (2021), and follow the Labour Inspection Convention (No. 81) of the International Labour Organization, 1947).

### 2.2 | PROVIDE APPROPRIATE SUPPORT FOR ALTERNATIVE CARE WORKERS

Support for alternative care workers can be organised in various ways. They should be enabled and encouraged to have access to *labour unions and institutional support*. This could be a first step for alternative care workers to have a place they can contact for support. *Chapter 5* shows the importance for community health workers receiving support in e.g. looking for jobs, administrative tasks or looking for childcare. Organisations that proactively raise awareness and inform alternative care workers about the rights they are entitled to should also be financially supported. FAIRWORK Belgium is an example of such an organisation. It aims to improve the situation of workers with precarious or lacking residence status through various facilities: 1) Helpdesk: employees can ask their questions, receive assistance in submitting complaints to the labour inspection, etc.; 2) Information about rights: through brochures, training courses, study days, websites, etc.; 3) Policy work: formulating policy proposals and lobbying to relevant policymakers; 4) Empowering domestic workers: organising weekly meetings for French classes, getting information about their rights, developing their network, etc. (FAIRWORK Belgium, 2021).

Peer learning and peer support show to be essential throughout *Chapters 4 and 5*. Especially for care workers with a migration background who do not have a broad social network in Belgium, this is a crucial factor to cope with certain challenges (e.g. for emotional support, explanation of care activities). However, it is not easy for care workers with a migration background to invest in building a social network, because of limited free time and opportunities to meet people. Initiatives to create social bonds among care workers with a migration background should therefore be encouraged and supported. The self-organised interest group for migrant live-in care workers in Austria, DREPT, responds to this by using online tools to strengthen migrant carers' solidarity networks and gain confidence in their position as caretakers. Online webinars and video tutorials deal with topics like labour rights, demanding these rights through civic engagement (petitions, contacting local authorities), care work and gender issues in care work. Additionally, online and offline community meetings are organised to create solidarity networks (Matei, 2021).

#### 2.3 | ORGANISE STRENGTHS-BASED EDUCATION FOR ALTERNATIVE CARE WORKERS

As mentioned in section 3.1 on valuation, previously acquired skills are not being sufficiently recognised. The Sustainable Development Goals, in target 4.4., include increasing opportunities for people with relevant skills: "By 2030, substantially increase the number of youth and adults who have relevant skills, including technical and vocational skills, for employment, decent jobs and entrepreneurship" (United Nations, 2015). Previously acquired skills should be recognised and strengthened, offering alternative care workers career opportunities. *Chapter 6* demonstrates that strengths-based education (Lopez & Louis, 2009) is effective towards taking into account previous experiences and skills. Strengths-based education "concentrates on the strengths, capacities and aspirations of individuals and uses these as a catalyst for positive change and growth" (Waterhouse & Virgona, 2008, p. 3). All too often, despite their potential high value previous experiences and skills go unrecognised and underutilised (Schuster et al., 2013). More training should apply the strengths-based approach to recognise and develop the strengths of individuals who might otherwise be perceived as underskilled. This is the reverse approach of the deficit model. Through strengths-based education, learners are recognised as the experts of their own lives, in which they know best what will work for them to reach change. The trainer has a facilitative role to identify, highlight and amplify strengths of the learner (Waterhouse & Virgona, 2008). *Chapter 5* further identifies that training for alternative care workers should not only focus on work-related competences, but also on broader life skills and social capital. For instance, personal development, employability, expanded social networks and social recognition are important training outcomes for community health workers.

Strengths-based education was previously used in formal higher education mainly to widen students' participation (e.g. Krutkowski, 2017; Pang et al., 2018; Soria & Stubblefield, 2015), yet it is also a meaningful approach in adult education. The strengths-based approach was previously also used for interaction with welfare clients, where values of respect, social justice, self-determination and the sharing of power are crucial (Waterhouse & Virgona, 2008). Additionally, adult learning principles and strengths-based education align well – namely, adults are motivated to learn when it answers questions that bother them – and relate directly to their lived experiences (Freire, 1972).

# 2.4 | USE AN INTERSECTIONAL LIFE COURSE PERSPECTIVE WHEN DEVELOPING POLICY AND PRACTICE FOR ALTERNATIVE CARE WORKERS

Based on the findings of this dissertation, we can conclude that when developing policies and practice for alternative care workers, the complex interactions between micro, meso and macro structures should be taken into account. After all, live-in migrant carers and community health workers move along a dynamic trajectory that derives from the interaction between human agency and various forces of social structure. One way to understand these complex interactions is through the intersectional life course perspective developed by Ferrer et al. (2017), originally conceived to understand the associations between structural and institutional forces that shape the everyday life narratives of older people at marginal and racialised social locations. We argue that it might also be applied to understand experiences of alternative care workers, because within the constraints of their social world alternative care workers still make choices that construct their life course.

The intersectional life course perspective consists of four steps. First, key life course events and their timing are identified, together with structural forces that contribute to these moments. This means that the life course perspective is extended beyond the individual level and considers interlocked lives between individuals and the influence of structures and institutions (e.g. retirement schemes, migration policy). Second, locally and globally linked lives are examined. This step takes into account that individual trajectories are not experienced in isolation, and moreover, when people organise their lives these are based on relationships with family, ancestors and across transnational contexts. Third, categories of difference and how they shape identities are explored. Here the structural and institutional relations that shape lived experiences are taken into account. This is where the intersectionality comes in, by identifying the categories of difference (e.g. gender, race). Fourth, the final step assesses how processes of differentiation (gendering, racialisation) and systems of domination (sexism, racism) shape lives, agency and resistance. This entails that lived experiences are contextualised within wider systems of domination. Although these systems of domination shape experiences, it is acknowledged that individuals can also overturn structural forces behind oppression and marginalisation (Ferrer et al., 2017).

The findings of the different chapters of this dissertation gives us confidence to argue that an intersectional life course perspective would inform our understanding of how e.g. gender, labour, care and migration are interconnected, and have important implications for the lived experiences of alternative care workers.

## 2.5 | GIVE VOICE TO ALTERNATIVE CARE WORKERS IN IMPACT EVALUATION

In recent years we have seen growing attention to measuring effectiveness, impact evaluations, impact assessments, etc. in different sectors (social work, care, education, policymaking). Throughout the studies, this dissertation has used several innovative methodologies that could inspire practice and policy interested in impact and evaluation. All methods have in common that they include alternative care workers as important participants and knowledge-holders.

The study in *Chapter 4* used a narrative approach underpinned by collective vignettes to present the results. Collective vignettes capture the complexity of situations in which actions are undertaken, with attached emotions and motivations (Polkinghorne, 1988). They depict participants' lived experiences in their own words. In that way, participants are seen as the experts of their own realities (Blodgett et al., 2011). Rather than analysing qualitative data from a thematical analysis approach or grounded theory (both focusing more on themes, categories, codes), vignette analysis really puts the narratives and the people at the centre.

The study in *Chapter 5* uses the Most Significant Change technique to collect and analyse the data in a participatory way. This technique allows gathering a rich description of changes and captures unexpected changes. As this approach does not focus on predefined indicators but includes the lived experiences of participants to study the outcomes of an intervention, it captures process outcomes that are not documented by traditional evaluation methods (Wilder & Walpole, 2008). The technique likewise allows for the inclusion of outcomes that were personally valued by trainees and for outcomes they found most significant (Choy & Lidstone, 2013). In this study we used a horizontal selection process to analyse and select the data. This entails that the selection process was done by other trainees, giving more weight to participants' priorities (Tonkin et al., 2021). It is therefore a useful tool when the impact on the users is identified, as opposed to vertical selection, which is made by employers higher in the hierarchy (Keinemans et al., 2020).

The study in *Chapter 6* uses the context-mechanism-outcome configuration to display the results. Through this technique the different project stakeholders are included in focus groups and individual interviews to include their voice on the project. This configuration addresses the questions of what works, how, for whom and under which circumstances, and acknowledges that evaluation and impact are not linear for a project (Dalkin et al., 2015).

By including voices of participant groups that are often perceived as hard-to-reach, it is essential to reflect upon which methods are suitable to reach and engage participants (Tourangeau et al., 2014). Creative methods have the benefits of stimulating discussion, encouraging deeper insights than questioning alone, and allowing participants to be more engaged (Rainford, 2020). 'Silent voices' which are often not heard in research can also be included through creative research methods, enabling participant empowerment. Sharing their experiences enables participants to be heard, recognised and acknowledged. By using such methods researchers are the facilitators, but the participants own the outcomes and share the knowledge as one of the aims is empowering the latter (Chambers, 1994). Efforts should be made to include these silent voices through accessible research/evaluation methods (Noordink et al., 2021).

## 2.6 | RETHINK FORMAL CARE SERVICES AND GLOBAL ECONOMIC PROSPERITY

Instead of thinking how live-in migrant carers can work in Belgium under good working and living conditions, do we need to rethink the organisation of formal care services and global economic prosperity so that alternative care workers do not need to exist?

If we look at live-in migrant care work, these jobs exist because older adults' care needs are not met by formal care services (*Chapter 3*), and migrant workers are motivated to leave their family and children behind, migrating mainly for economic reasons (i.e. hardship in their country of origin) (Chapter 4). The question can be raised as to whether the best option would be to optimise live-in migrant care workers' situation in Belgium, or make it unnecessary for them to work in Belgium under these optimised conditions. In order to make their work and migration unnecessary, two issues need to be addressed. First, older adults' care needs should be addressed by formal care services. This would make it unnecessary for them to look for care services outside the legal boundaries of formal care services. As addressed in *Chapter 3*, older adults are motivated to hire live-in migrant care workers because of a need for person-centred and continuous care and to be in control of their care process. Formal care services should respond to these motivations. Second, Chapter 4 demonstrates that live-in migrant care workers are mainly motivated to migrate and perform live-in care work due to an urge for economic betterment and to fulfil parental duties. As previous literature already pointed out that the absence of decent jobs in the home country pushes people into migration (Villarreal & Blanchard, 2013), providing decent jobs with attractive salaries would make migration of live-in migrant care workers unnecessary. This would also prevent them from the adverse consequences of their migration, such as leaving their family behind and having to build a new social network.

# 3 | CRITICAL REFLECTIONS AND SUGGESTIONS FOR FUTURE RESEARCH

In interpreting the findings of this dissertation, some overall critical reflections should be acknowledged. These reflections will be discussed in this section, together with some suggestions to overcome them in future research.

# 3.1 | CONCEPTUALISING AND CONDUCTING THE STUDIES: NEED FOR AN INTERDISCIPLINARY APPROACH

Research on migrant care work is situated at the intersection of migration, care and employment. While my educational background (adult educational sciences and development studies) captures these topics, this research would benefit from an interdisciplinary approach. Interdisciplinary research is defined as "any study or group of studies undertaken by scholars from two or more distinct scientific disciplines. The research is based upon a conceptual model that links or integrates theoretical frameworks from those disciplines, uses study design and methodology that is not limited to any one field, and requires the use of perspectives and skills of the involved disciplines through out multiple phases of the research process" (Aboelela et al., 2007, p. 341). Individuals rarely have the expertise to facilitate a multidimensional research topic and therefore need to take a broader perspective than their own discipline. An interdisciplinary research teams considers the dynamics of the different disciplines (Lakhani et al., 2012). Even though some studies included in this dissertation were conducted together with co-authors from disciplines like sociology, social and mental health, end-of-life care, and anthropology, the research would have benefitted from the incorporation of these (and more, e.g. law, migration, political sciences) disciplines at an earlier stage. Future researchers investigating topics concerning migrant care work might therefore be advised to work in interdisciplinary research teams consisting of different disciplines, such as sociology, law, nursing and gender studies.

# 3.2 | INCLUDING RESPONDENTS IN RESEARCH: NEED FOR A TRUST RELATIONSHIP

Including alternative care workers as respondents in research can be challenging. Researchers' access to certain groups might be difficult because of their social or physical location, vulnerability or hidden nature (Ellard-Gray et al., 2015). The community health workers and live-in migrant care workers included in this dissertation were recruited through different strategies.

Community health workers were first contacted and asked to participate by the programme managers with whom they had a good contact. The programme managers informed the interested community health workers that they would be contacted by the researcher. Thereafter the researcher provided more information to the community health worker and together they set up a date for the interview or focus group. This strategy proved to work to include community health workers in the research. An important factor here was that the respondents already trusted the programme managers and this trust was passed on to the researcher. The researcher too had a good contact and a sustainable relationship with the programme managers.

Including live-in migrant care workers proved to be more challenging. Especially having access to live-in migrant care workers was difficult. The researcher reached out to organisations that possibly had contacts who could participate. However, it appeared to be important as a researcher to first have a trust relationship with an organisation before it would be willing to engage their contacts. Some

organisations the researcher had longer contacts with were interested in addressing their contacts. Otherwise, an initial videocall could also help provide additional information and clarify doubts. It is crucial that these organisations be also appreciated for their engagement, for instance by providing information on the overall findings (Patel et al., 2018).

Once the researcher was in contact with a potential respondent, it was important to first create a relationship of trust before having the interview (Ellard-Gray et al., 2015). Not all live-in migrant care workers were immediately willing to participate in an interview. However, after taking the time to explain the relevance of the research, listen to their doubts, answer their questions honestly and transparently, and build a respectful relationship, some did agree to participate.

Future researchers should bear in mind the importance of a trust relationship both with organisations they contact and with potential respondents before having an interview.

#### 3.3 | COMPOSITION OF RESPONDENTS: NEED FOR MULTI-STAKEHOLDER PERSPECTIVE

The different studies of the dissertation include a broad range of stakeholders in the data collection. The studies on live-in migrant carers include interviews and focus groups with live-in migrant carers, older adults, family members of older adults and professionals. The studies on community health workers include interviews and focus groups with community health workers, trainers, care employees and project coordinators. The multi-stakeholder perspective enables understanding the multiple perspectives in the delivery of care. Including multiple perspectives provides a more nuanced and comprehensive understanding of interactional systems (Vogl et al., 2018). A multi-stakeholder perspective is especially interesting when it is assumed that different views exist on the same experience (Reczek, 2014).

On the other hand, challenges of a multi-stakeholder perspective entail interpreting contradictory findings between different stakeholders (Vogl et al., 2018). In this study, an explicit choice was made to represent the different perspectives, and if necessary provide details on the involved group of stakeholders (while remaining confidential). It was also found that by including multiple perspectives there was less opportunity to explore one single perspective in depth. For instance, in *Chapter 6* the different stakeholder perspectives are included to build the context-mechanism-outcome configuration. In that study the perspectives are often complementary. In *Chapter 4*, the focus lies on the perspective of live-in migrant carers through a narrative approach, which benefits from incorporating only one perspective and which explores this one perspective in depth.

Hence depending on the purpose of the study, using a multi-stakeholder perspective can provide a more comprehensive understanding for future researchers.

# 3.4 | CONDUCTING INTERVIEWS: NEED FOR AN ENABLING SPACE TO SHARE EXPERIENCES

While conducting the different studies for this dissertation, we felt the need to create an enabling space to share experiences. This space consisted of using online interviews and interviewing in a second language.

The studies in *Chapters 4 and 5* are conducted using *online interviews*, due to COVID-related social distancing recommendations. Online interaction made it challenging to create a trust relationship and obtain in-depth information, as also experienced by other researchers conducting

online interviews (e.g. Dos Santos, 2020). This researcher also experienced a distance between participant and researcher. However, conducting serial interviews, as in *Chapter 4*, stimulated this familiarity and trust in which participants felt more comfortable to share experiences. It is already argued in previous literature that online interviews have a negative effect on participants' concentration (Deakin & Wakefield, 2013). For researchers too it is more challenging to stay focused during online interactions. On the other hand, participants often had limited time and thus online interviews created a convenient way to meet, as also experienced by Janghorban et al. (2014).

The different studies include several interviews and focus groups conducted in a *second language* of both the researcher and the participant. This implies that both parties' language skills might have affected the dynamics of the interview or focus group in various ways, such as misunderstandings or interviewer and response bias (e.g. socially desirable answers, phrasing questions differently). Additionally, some important cues like non-verbal communication or nuances might be missed (Marschan-Piekkari & Reis, 2004). To minimise these issues, different strategies were adopted in the studies. First, in most cases the researcher spoke the different languages in which the interviews were conducted (only one interview was conducted with an interpreter), therefore a translation was not needed for data analysis and original nuances and subtleties were not lost in the process. It does remain challenging in certain cases to translate some wordings into the language of publication. Prior to the interview the questions were examined for wording and understandability through discussion with the co-authors. During the interview itself, interviewer and participant could ask clarifying questions as needed.

Future researchers should create an enabling space to share experiences by taking appropriate measures when conducting online interviews and when interviewing in a second language.

#### 3.5 | DETERMINING THE DATA SET: REACHING SATURATION

The chapters in this dissertation are based on rather small sample sizes. Several reasons explain this size. First, a small sample of live-in migrant care workers and older adults was used due to the challenges in recruiting this group (e.g. the sensitivity and secrecy of live-in migrant care workers). Second, the project with community health workers included every edition only 10 community health workers.

To determine the point in which sufficient information was collected, we used data saturation. Different models of saturation exist and differ in the extent to which an inductive or deductive approach is adopted and on when saturation is defined in the research process. Saunders et al. (2018) define four models of saturation (see Table 9). First, *theoretical saturation* refers to grounded theory and uses the development of the emerging theory in the sampling process as the criterion. Second, *inductive thematic saturation* focuses on the identification of new codes or themes during data analysis and thus not focus on the completeness of theories. Third, *a priori thematic saturation* uses another logic and collects data to exemplify a theory. It thus points to predetermined theoretical categories during the sampling phase. Fourth, *data saturation* relates to the degree in which new data repeat what has been expressed in previous data during the data collection, without wanting to thick all the themes generated by a theory. The chapters in this dissertation make use of *data saturation*, the fourth model, to determine the point when sufficient interviews have been carried out. This means that during the data collection phase the author and co-authors identified whether new themes were coming up in

the interviews, regarding to the previous ones. This data collection phase was an iterative process with the data analysis phase.

In addition to this data saturation among the interviews (the dataset as a whole), saturation can also be reached within interviews (Legard et al., 2003). This is especially of importance in narrative research. In this case, saturation is reached when the researcher has captured a full understanding of the individual respondent's perspective. Therefore, saturation within interviews is located in the data collection phase.

Finally, there is discussion on an academic level whether it is always necessary for qualitative research to reach data saturation. Fusch and Ness (2015) argue that researchers should think of data in terms of rich and thick, in which rich is defined as quality and thick as quantity. Richness of information depends on the topic and the resources available (O'Reilly & Parker, 2012). Therefore, future researchers are recommended to critically take into account the concept of data saturation and should not only focus on an amount of data to reach, but look at the richness of data mostly.

| Model                         | Description  | Principal          |
|-------------------------------|--|--------------------|
|                               |  | focus              |
| Theoretical saturation        | Relates to the development of theoretical categories; related to grounded theory methodology | Sampling           |
| Inductive thematic saturation | Relates to the emergence of new codes or themes  | Analysis           |
| A priori thematic saturation  | Relates to the degree to which codes or themes are exemplified in the data                   | Sampling           |
| Data saturation               | Relates to the degree to which new data repeat what was expressed in previous data           | Data<br>collection |

TABLE 9 Models of saturation and their principal foci in the research process (Saunders et al., 2018)

# 3.5 | REFLECTING ON GENDER WHEN CONDUCTING RESEARCH WITH ALTERNATIVE CARE WORKERS

The findings of this dissertation echo certain gender constructions in society (e.g. the vast majority of care workers being women, being strongly motivated by parental duties, low status attached to care work) (Eurofound, 2020; Peterson, 2018). However, conducting this research we did not take into account how gender shapes experiences of alternative care workers – for instance how gender plays a role in their motivation to migrate and perform care work or in their empowerment. The gender perspective can offer future researchers interesting insights on the influence of gender on alternative care workers and their lived experiences, and how gender might shape structural barriers. This gender perspective should be considered from the start of the research, when conceptualising the research, recruiting participants, to performing the analyses and writing recommendations for policy and practice (INSTRAW, 2007).

#### 3.6 | REFLECTING ON THE TERMINOLOGY USED FOR 'ALTERNATIVE CARE WORKERS'

In this dissertation we used the term 'alternative care workers' to refer to both live-in migrant care workers and community health workers. However, some reflections should be made on this terminology. We first outline our questioning of '*alternative*' care workers, then address the use of care '*workers*' and care '*professionals*', and last we explain why we often refer to the migration background of live-in migrant carers and community health workers.

#### 3.6.1 USE OF 'ALTERNATIVE CARE WORKERS'

In this dissertation we often use the term 'alternative care workers' to refer to both live-in migrant care workers and community health workers. However, a critical note concerning the term 'alternative' should be made. As suggested by the concept of healthcare bricolage, individuals use multiple health resources from multiple places to answer their health concerns; these include various caring practices and transnational networks (Phillimore et al., 2019). This makes us question the normativity of the term 'alternative' used. To what extent are those care workers alternative? To whom are they alternative? To which point of reference do we conceptualise care workers as alternative? Is this point of reference then sufficient to answer older adults' care needs? By asking these questions, we argue that these alternative care workers should be included in the care diamond as conceptualised by Razavi (2007). This would also answer the critique on the care diamond being Eurocentric and overlooking alternative care providers (Radziwinowiczówna et al., 2018; Raghuram, 2016). Currently, the care diamond captures four main actors in care provision: family, private market, state, not-forprofit sector. We argue that the conceptualisation of the private market should be broadened to also include individuals working for profit and thereby acknowledging different kinds of 'alternative' markets. In *Chapters 3 and 4* we outlined that live-in migrant carers were mainly employed in two ways: through employment agencies or through acquaintances (often without legal employment contracts).

#### 3.6.2 USE OF 'CARE WORKERS'

Supplementing the terms 'live-in migrant care *workers*' and 'community health *workers*', in this dissertation we use the term 'alternative care *workers*'. Looking back, we question why we do not use the term 'alternative care *professionals*', as this would value their professional status. The use of 'alternative care *worker*' contributes, albeit unintentionally, to the abovementioned issues with valuation (see section 3.1). For instance, societal valuation in which alternative care work is often perceived as low status, and needing low-skilled care workers, would benefit from professional recognition. If we continue to use the term care *worker*, we continue to point out that they are not perceived as fully professional and contribute to their low societal value, whereas we want to achieve the opposite effect.

#### 3.6.3 REFERRING TO THE MIGRATION BACKGROUND

In this dissertation, we often refer to the migration status of alternative care workers. A critical note concerning the term 'migrant' should be made for both live-in migrant carers and community health workers. First, we would like to explain the rationale why we use both the terms 'live-in *migrant* carer' and 'live-in carer' when talking about the same persons. We used 'live-in *migrant* care worker/carer' when their migrant status was relevant (e.g. when certain experiences originated from

their migration). However, when the migrant status was not the main focus (e.g. when their experience stemmed from their role as carer or from the fact they were live-in), we deliberately chose to use the term 'live-in carer'. We did not want to succumb to the pitfall of othering, in which a person is labelled as someone who belongs to an 'other' social group, stereotyping them and creating thinking in terms of 'us' versus 'them' (Torres, 2006). As Torres and Lindblom (2020) argue in their study on media representation of care workers with a migration background in Sweden, othering of care workers with a migration background is often done by labelling those individuals as an asset to the care sector because of their different characteristics from the majority population, yet this othering is also the reason why they are depicted as a 'reserve army'. This negatively contributes to the recognition of domestic work and valuation of care.

Second, the participant group of community health workers was diverse in terms of arrival in Belgium. Some arrived a few months before the work-training programme started, others were born in Belgium and were second-generation migrants. This makes us question the reference to their migration background, as also the European Commission explains their use of the term secondgeneration migrants: "Strictly this term does not relate to a migrant, since the person concerned has not undertaken a migration, but the term is included as it is commonly used in publications and the media" (European Commission, 2022). Furthermore, using the term second-generation underlines that this group is not perceived as belonging to the country in which they are born, seeing them as foreigners. It does mark their exclusion from society and their precarious situation as descendants of migrants (Chimienti et al., 2019). For this reason it might still be useful to refer to their migration background in research, when topics of exclusion are at play.

#### 4 | GENERAL CONCLUSION

This dissertation contributes to the understanding of alternative care workers in addressing older adults' unmet care needs. Using different methodologies (narrative research, Most Significant Change and Context-Mechanism-Outcome configuration), this dissertation explores the potential of alternative care workers, such as live-in migrant carers and community health workers. The findings demonstrate that alternative care workers' potential in addressing older adults' care needs lies in increasing acceptability, adequacy and awareness of care services. Alternative care workers can be empowered through peer learning and peer support. Also recognition of their profession, societal recognition and recognition of their experience, knowledge and skills contributes to their empowerment. Care organisations might be empowered to better address older adults' care needs through mutual learning between alternative care workers and care employees and through learning from shortcomings in the care offering. This dissertation concludes with recommending a genuine valuation of alternative care workers, economically, socially and politically. Furthermore, strengthsbased education should be organised for alternative care workers to take into account their previously acquired experiences and skills. In addition, an intersectional life course perspective should be used when developing policy and practice for alternative care workers to consider the complex interactions between micro, meso and macro structures.

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# ENGLISH SUMMARY

## 1 | RATIONALE AND RESEARCH AIM

The heterogeneous older population in Belgium comes with diverse care needs, so a one-size-fitsall approach does not work (Van Eenoo et al., 2018). Access to care services is not realised for all, as certain needs are not addressed in the formal care offering and several barriers hinder access. However, when facing barriers older people's needs are often pointed to as 'special', requiring interventions to fit into mainstream services and blaming individuals for the barriers they are facing (Phillimore et al., 2019). Additionally, care has previously been defined in a rather Eurocentric way (Radziwinowiczówna et al., 2018; Raghuram, 2016), by identifying the four institutions providing care (family, market, state, not-for-profit sector) (Razavi, 2007). Given the lack in research, we consider the diversity of care provision and have attention for alternative care workers, such as community health workers and live-in migrant care workers. The overall aim of this dissertation is to **explore alternative approaches in organising care for older adults whose care needs are currently not met by formal care services.** Three sub-aims are formulated on different levels, to look beyond older adults' needs and also include care workers and care organisations:

- 1. To explore the potential of alternative care workers in addressing older adults' unmet care needs
- 2. To explore how alternative care workers can be empowered to better address diverse care needs of older adults
- 3. To explore how care organisations can be empowered to better address diverse care needs of older adults

This dissertation uses different qualitative research methods to answer the research aim. The data collection consists of two parts: one concerning live-in migrant care workers, and a second one concerning community health workers.

### 2 | DISCUSSION OF THE MAIN FINDINGS IN RELATION TO THE RESEARCH AIM

In order to answer the research aim, four studies have been carried out:

- Study 1 (Chapter 3) includes qualitative research into older adults' and informal caregivers' motivations and experiences in hiring live-in migrant care workers.
- Study 2 (Chapter 4) uses a narrative approach underpinned by collective vignettes to investigate live-in migrant care workers' decisions to migrate, encountered personal and social changes and strategies to cope with working and living conditions.
- Study 3 (Chapter 5) applies the Most Significant Change technique to examine the changes experienced by community health workers during a work-training program.
- Study 4 (Chapter 6) uses the Context-Mechanism-Outcome configuration to evaluate the work-training program for community health workers by including different project stakeholders.

# RESEARCH AIM 1: TO EXPLORE THE POTENTIAL OF ALTERNATIVE CARE WORKERS IN ADDRESSING OLDER ADULTS' UNMET CARE NEEDS

First, alternative care workers increase the *acceptability* of care. Acceptability is defined by whether older adults are comfortable with the characteristics of the care service. As shown in Chapter 3, livein migrant carers increase acceptability of care by providing person-centred and continuous care. This makes it possible to build a relationship of trust, whereby the specific needs of the older adult are taken into account. Furthermore, older adults appreciate being cared for by one and the same person rather than by different actors. In addition, having a voice in care and retaining mastery over their lives are important motivations. In addition, Chapter 6 reveals that community health workers show the importance of taking into account cultural preferences for the acceptability of care. As one of the outcomes of the community health worker-programme was the increase in cultural competence of the care services, a lower threshold for migrant families to the care organisation and increased acceptability for a diverse group of older adults is realised. By applying the cultural competence model of Sharifi et al. (2019), community health workers are strongly committed to increase the extent to which older people feel comfortable with the presence of the care provider and thus boost the acceptability of care services.

Second, alternative care workers contribute to the *adequacy* of care services. Adequacy is defined by the extent to which care organisations operate practically in ways that meet the preferences of older adults. Chapter 3 demonstrates that live-in migrant care workers' 24-hour presence contributes to adequate care. According to older adults and health professionals, the need for 24-hour care cannot be met by formal care services, since they would have to call on different care services for different tasks, organising their lives around the schedules of the care professionals. The permanent presence of the same live-in carer responds to these concerns and ensures that they retain control over their lives.

Third, alternative care workers increase *awareness* on care services. Awareness is defined as providing effective communication and information with relevant users. Previous research already pointed out that the lack of clear information and knowledge about appropriate routes to get access to care prevents older adults from reaching formal care services (Suurmond et al., 2016). Findings of Chapter 6 demonstrate that community health workers create awareness on the existence and functioning of care services. They develop cultural skills that enable them to address and inform older adults in a more qualitative way, and work on a relationship of trust. Consequently, older adults are better informed and find access to care services.

### RESEARCH AIM 2: TO EXPLORE HOW ALTERNATIVE CARE WORKERS CAN BE EMPOWERED TO BETTER ADDRESS DIVERSE CARE NEEDS OF OLDER ADULTS

Live-in migrant carers are mainly empowered through personal life choices and associated personal and social changes, while community health workers are mainly empowered through the work-training programme. This dissertation reveals specific elements that can contribute to the empowerment of alternative care workers, among which peer learning and peer support, and recognition.

First, alternative care workers can be empowered through peer learning and peer support to better address diverse care needs of older adults. Chapter 5 demonstrates that peer learning and peer

support can take place formally in class when time and space is provided to share experiences and thus when there are also instructions in the form of a class assignment, as well as through informal contacts between community health workers after class. Chapter 6 describes group-based learning, in which group interaction is valued during the training (Roy & Lin, 1993), to create a safe learning space and increase the motivation for learning. Additionally, community health workers in the training were sharing practical examples and each person would bring in another insight based on their background and experience. They were encouraged by the trainers to have an open attitude and look together for solutions to case studies. Additionally, Chapter 4 demonstrates that peer support is indispensable for live-in migrant carers to cope with harsh working and living conditions. They are looking for other migrant workers from the same country through social media and employment agencies to meet in Belgium. Having the same experiences with working and living conditions creates bonds of solidarity and perseverance between them. Even though it is challenging to build a social network in the host country, because of limited free time, short stay in the host country, etc. This incentivizes most live-in migrant carers to also look for transnational support from close family and friends who are still living in the home country.

Second, alternative care workers can be empowered through recognition of the profession, societal recognition and recognition of experience and knowledge.

Regarding *recognition of the profession*, Chapter 3 and 4 indicate that several questions are raised on the training, employment conditions and legal status of live-in migrant care workers. The often precarious migrant status, isolation from organisational sources of support and lack of information for both parties contribute to poor working conditions and uncertainty about the quality of care. Also Chapter 6 points out that the specific job of community health workers as defined in the Brussels project, is not (yet) a recognised profession. The lack of a legal framework for the profession limits the formal care organisations in permanently integrating health workers structurally. Recognition of the profession is crucial in the empowerment, as professional status also serves as a gatekeeping function. Rules, regulations, credentialing, and responsibilities are attached to the status, which can benefit instrumental rewards (such as access to training or a physical working location).

Regarding *societal recognition*, Chapter 4 demonstrates that it is not evident for all live-in migrant care workers to feel recognized in their work by their social environment. This lack of recognition often stems from negative connotations attached to providing live-in care such as having a low-paid job or performing domestic work. Experiencing more social recognition, such as acknowledging that they often financially support their families from a distance or more appreciation from the relatives of the older person they provide care for, can help live-in carers feel proud of their work and feel recognised by those around them. Furthermore, community health workers highly value in Chapter 5 the societal recognition they receive from community members through their work. This is part of an increased social capital, which empowers them to enact change and advance their social position.

Regarding *recognition of experience and knowledge*, this dissertation demonstrates that the majority of involved live-in migrant carers in our studies did not follow a formal nursing education. However, Chapter 3 points out that participants (care receivers, employment agencies and formal care professionals) believe the live-in migrant carers acquired the necessary skills to perform live-in care through previous care experiences with family members or personal qualities and characteristics (e.g. being committed or cheerful). In addition, Chapter 6 demonstrates that the knowledge and skills of community health worker trainees are recognized through applying strengths-based education (Lopez & Louis, 2009) in the work-training programme. In this way, their competences and strengths can be

identified, recognised and affirmed. All too often, skills of jobseekers go unrecognised and underutilised (Schuster et al., 2013), perceiving them as underskilled despite their potential high value for the job.

# RESEARCH AIM 3: TO EXPLORE HOW CARE ORGANISATIONS CAN BE EMPOWERED TO BETTER ADDRESS DIVERSE CARE NEEDS OF OLDER ADULTS

This dissertation reveals that mutual learning between alternative care workers and care employees, and learning from shortcomings in the care offering can empower care organisations to better address diverse care needs of older adults.

First, Chapter 6 demonstrates that mutual learning between community health workers and care employees entails exchanging knowledge, ideas and experiences and learning from each other. Mutual learning asks strong commitment and engagement from care organisations. In order to enable mutual learning, a fully supportive context should be created. Therefore, creating opportunities for community health workers to participate actively in the care organisation is essential, otherwise the transfer of knowledge of the community health worker to the entire organisation will be limited. This requires investment in cultural competence for the entire organisation, at different levels of the organisation and not only for some of its often-lower-level employees. Chapter 5 additionally highlights the need of community health workers for mentoring, in which both the internship mentor (often a care employer), as the community health worker trainee can share experiences and learn from each other. Building on this finding, we can conclude that care organisations can play an important role in mentoring.

Second, regarding learning from shortcomings in the care offering, while addressing the motivations of older adults and their families to hire live-in migrant carers, Chapter 3 reveals shortcomings in the formal care offering. Formal services are often either insufficient for older adults to be able to age in place (e.g. lack of 24-hour care guarantee) or do not meet their needs and preferences. Care organisations could learn from their motivations by adapting their services to the needs of older adults (e.g. enabling older adults to retain mastery when in care services, providing person-centred and continuous care). In addition, Chapter 6 indicates that active involvement of a community health worker can point care organisations on shortcomings in their offering and stimulate them in working more cultural competent. However, it remains difficult to obtain a change on the deep structure of the care organisation, meaning that the care offering is developed and adjusted to the target group and not the other way around.

### 3 | IMPLICATIONS FOR POLICY, PRACTICE AND FUTURE RESEARCH

Based on the results of this dissertation, several implications for policy, practice and future research can be made.

In the field of policy and practice, first, alternative care workers should be valued economically, socially and politically. This includes fair remuneration, as our findings demonstrate that alternative care workers are often economically responsible for their family. The societal valuation of alternative care workers is reflected in the low status attached to their work and perceptions of low-skilled workers. Additionally, alternative care workers should be politically valued, as political regulations can shape the working and living conditions. For live-in migrant carers, a formal employment status

will reduce precariousness. Community health workers will benefit a formal employment status to recognise their professional status and entitle them to institutional support and instrumental rewards.

Second, strengths-based education for alternative care workers should be organised. In this way, previously acquired skills are recognised and strengthened. All too often, their experiences and skills go unrecognised and underutilised, despite their high potential.

Third, an intersectional life course perspective should be used when developing policy and practice for alternative care workers. This will allow to take into account the complex interactions between micro, meso and macro structure and assess the implications for the lived experiences of alternative care workers.

Several recommendations for future research can be drawn from this dissertation. First, future research should bear in mind the importance of a trust relationship both with organisations who they contact for recruiting respondents and with possible participants before having an interview.

Second, future research should create an enabling space to share experiences. This entails taking appropriate measures when conducting online interviews or when interviewing in a second language.

Third, future research is suggested to incorporate a multi-stakeholder perspective. This provides a more nuanced and comprehensive understanding of interactional systems. A multi-stakeholder perspective will enable research to understand the multiple perspectives in the delivery of care.

### NEDERLANDSTALIGE SAMENVATTING

#### 1 | RATIONALE EN ONDERZOEKSDOEL

De heterogene oudere bevolking in België komt met diverse zorgnoden, waardoor een standaardaanpak niet werkt (Van Eenoo et al., 2018). De toegang tot zorgvoorzieningen wordt niet voor iedereen gerealiseerd, omdat bepaalde noden niet aan bod komen in het formele zorgaanbod en verschillende barrières de toegang belemmeren. Wanneer ouderen met barrières te maken krijgen, wordt vaak verwezen naar hun noden als 'speciaal', waarvoor interventies nodig zijn om in de reguliere diensten te passen en individuen de schuld krijgen van de barrières waarmee ze te maken krijgen (Phillimore et al., 2019). Daarnaast is zorg eerder op een eurocentrische manier gedefinieerd (Radziwinowiczówna et al., 2018; Raghuram, 2016), door de vier instellingen die zorg verlenen te identificeren (familie, markt, staat, non-profitsector) (Razavi, 2007). Gezien het gebrek aan onderzoek, bestuderen we de diversiteit aan zorgverleningsdiensten en hebben we aandacht voor alternatieve zorgverleners, zoals community health workers en live-in migrant carers. Het algemene doel van dit proefschrift is het verkennen van alternatieve benaderingen in het organiseren van zorg voor ouderen aan wiens zorgnoden momenteel niet wordt voldaan door formele zorgdiensten. Er worden drie subdoelen geformuleerd op verschillende niveaus, om verder te kijken dan de noden van ouderen en ook zorgverleners en zorgorganisaties erbij te betrekken:

- 1. Het potentieel van alternatieve zorgverleners onderzoeken om tegemoet te komen aan de onvervulde zorgnoden van ouderen
- 2. Nagaan hoe alternatieve zorgverleners empowered kunnen worden om beter in te spelen op de diverse zorgnoden van ouderen
- 3. Nagaan hoe zorgorganisaties empowered kunnen worden om beter in te spelen op de diverse zorgnoden van ouderen

Dit proefschrift maakt gebruik van verschillende kwalitatieve onderzoeksmethoden om het onderzoeksdoel te beantwoorden. De dataverzameling bestaat uit twee delen: een deel over live-in migrant carers, en een tweede deel over community health workers.

# 2 | BESPREKING VAN DE BELANGRIJKSTE BEVINDINGEN MET BETREKKING TOT HET ONDERZOEKSDOEL

Om het onderzoeksdoel te beantwoorden, werden vier studies uitgevoerd:

- Studie 1 (Hoofdstuk 3) omvat kwalitatief onderzoek naar de motivaties en ervaringen van ouderen en mantelzorgers met betrekking tot het tewerkstellen van live-in migrant carers.
- In studie 2 (Hoofdstuk 4) wordt aan de hand van een narratieve benadering, ondersteund door collectieve vignetten, onderzoek gedaan naar de motivaties van live-in migrant carers om te migreren, de persoonlijke en sociale veranderingen waarmee ze worden geconfronteerd en de strategieën om met de werk- en leefomstandigheden om te gaan.
- In studie 3 (Hoofdstuk 5) wordt de Most Significant Change-techniek toegepast om de veranderingen te onderzoeken die community health workers tijdens een werktrainingsprogramma hebben ervaren.

 Studie 4 (Hoofdstuk 6) gebruikt de Context-Mechanisme-Outcome configuratie om het werktrainingsprogramma voor community health workers te evalueren door verschillende belanghebbenden van het project te betrekken.

### ONDERZOEKSDOELSTELLING 1: HET POTENTIEEL VAN ALTERNATIEVE ZORGVERLENERS NAGAAN OM TEGEMOET TE KOMEN AAN DE ONVERVULDE ZORGNODEN VAN OUDEREN

Ten eerste verhogen alternatieve zorgverleners de betrouwbaarheid van de zorg. Betrouwbaarheid wordt gedefinieerd door de vraag of ouderen zich prettig voelen bij de kenmerken van de zorgdienst. Zoals in Hoofdstuk 3 is aangetoond, verhogen live-in migrant carers de betrouwbaarheid van de zorg door persoonsgerichte en continue zorg te verlenen. Dit maakt het mogelijk een vertrouwensrelatie op te bouwen, waarbij rekening wordt gehouden met de specifieke noden van de ouderen. Ouderen waarderen het dat ze door één en dezelfde persoon worden verzorgd in plaats van door verschillende actoren. Daarnaast zijn het hebben van een stem in zorg en het behouden van zeggenschap over hun leven belangrijke motivaties. Verder blijkt uit Hoofdstuk 6 dat community health workers laten zien hoe belangrijk het is om rekening te houden met culturele voorkeuren voor de aanvaardbaarheid van zorg. Aangezien een van de uitkomsten van het programma voor community health workers de toename van culturele competentie van de zorgdiensten was, wordt een lagere drempel voor migrantengezinnen naar de zorgorganisatie en een grotere betrouwbaarheid voor een diverse groep ouderen gerealiseerd. Door het culturele competentiemodel van Sharifi et al. (2019) toe te passen, zetten community health workers zich sterk in om de mate waarin ouderen zich comfortabel voelen bij de aanwezigheid van de zorgverlener te vergroten en daarmee de betrouwbaarheid van de zorgdiensten te versterken.

Ten tweede dragen alternatieve zorgverleners bij aan de *bruikbaarheid* van de zorgverlening. Bruikbaarheid wordt gedefinieerd door de mate waarin zorgorganisaties praktisch opereren op een manier die tegemoetkomt aan de voorkeuren van ouderen. Hoofdstuk 3 laat zien dat de 24-uurs aanwezigheid van live-in migrant carers bijdraagt aan adequate zorg. Volgens ouderen en zorgverleners kan de behoefte aan 24-uurszorg niet worden vervuld door formele zorgdiensten, omdat ze voor verschillende taken een beroep zouden moeten doen op verschillende zorgdiensten en hun leven zouden moeten organiseren rond de roosters van de zorgverleners. De permanente aanwezigheid van dezelfde live-in migrant carer komt aan deze bezorgdheid tegemoet en zorgt ervoor dat zij de controle over hun leven behouden.

Ten derde vergroten alternatieve zorgverleners de *bekendheid* van zorgdiensten. Bekendheid wordt gedefinieerd als het verstrekken van doeltreffende communicatie en informatie aan relevante gebruikers. Eerder onderzoek wees er al op dat het gebrek aan duidelijke informatie en kennis over geschikte routes om toegang tot zorg te krijgen, ouderen ervan weerhoudt om formele zorgdiensten te bereiken (Suurmond et al., 2016). Bevindingen van Hoofdstuk 6 laten zien dat community health workers bekendheid creëren over het bestaan en functioneren van zorgdiensten. Ze ontwikkelen culturele vaardigheden die hen in staat stellen om ouderen op een meer kwalitatieve manier aan te spreken en te informeren, daarbij werken ze ook aan een vertrouwensrelatie. Bijgevolg zijn ouderen beter geïnformeerd en vinden ze toegang tot zorgdiensten.

# ONDERZOEKSDOELSTELLING 2: NAGAAN HOE ALTERNATIEVE ZORGVERLENERS EMPOWERED KUNNEN WORDEN OM BETER IN TE SPELEN OP DE DIVERSE ZORGNODEN VAN OUDEREN

Live-in migrant carers worden voornamelijk empowered door persoonlijke levenskeuzes en daarmee gepaard gaande persoonlijke en sociale veranderingen, terwijl community health workers voornamelijk empowered worden door het werk-trainingsprogramma. Dit proefschrift onthult specifieke elementen die kunnen bijdragen aan de empowerment van alternatieve zorgverleners, waaronder peer learning en peer support, en erkenning.

Ten eerste kunnen alternatieve zorgverleners door middel van peer learning en peer support in staat worden gesteld om beter in te spelen op de diverse zorgnoden van ouderen. Hoofdstuk 5 laat zien dat peer support en peer learning formeel in de klas kunnen plaatsvinden wanneer er tijd en ruimte is om ervaringen uit te wisselen en er instructies zijn in de vorm van een klassikale opdracht, maar ook door informele contacten tussen community health workers na de les. Hoofdstuk 6 beschrijft groepsgebaseerd leren, waarbij groepsinteractie wordt gewaardeerd tijdens de training (Roy & Lin, 1993), om een veilige leerruimte te creëren en de motivatie om te leren te vergroten. Daarnaast delen de community health workers in de training praktijkvoorbeelden en brengt iedereen een ander inzicht in op basis van zijn achtergrond en ervaring. Ze worden door de trainers aangemoedigd om een open houding aan te nemen en samen te zoeken naar oplossingen voor casussen. Daarnaast blijkt uit Hoofdstuk 4 dat peer support onontbeerlijk is voor live-in migrant carers om om te gaan met de zware werk- en leefomstandigheden. Ze zoeken via sociale media en uitzendbureaus naar andere werkers met een migratieachtergrond uit hetzelfde land om elkaar in België te ontmoeten. Het hebben van dezelfde ervaringen met werk- en leefomstandigheden schept banden van solidariteit en doorzettingsvermogen tussen hen. Al is het een uitdaging om een sociaal netwerk op te bouwen in het gastland, vanwege de beperkte vrije tijd, het korte verblijf in het gastland, enz. Dit stimuleert de meeste live-in migrant carers om ook transnationale steun te zoeken bij naaste familie en vrienden die nog in het thuisland wonen.

Ten tweede kunnen alternatieve zorgverleners empowered worden door erkenning van het beroep, maatschappelijke erkenning en erkenning van ervaring en kennis.

Wat de *erkenning van het beroep* betreft, blijkt uit Hoofdstuk 3 en 4 dat er verschillende vragen rijzen over de opleiding, de arbeidsvoorwaarden en de rechtspositie van live-in migrant carers. De vaak onzekere migrantenstatus, het isolement van organisatorische steunbronnen en het gebrek aan informatie dragen bij tot slechte arbeidsomstandigheden en onzekerheid over de kwaliteit van de zorg. In Hoofdstuk 6 wordt er ook op gewezen dat het specifieke beroep van community health workers, zoals gedefinieerd in het Brusselse project, (nog) geen erkend beroep is. Het ontbreken van een wettelijk kader voor het beroep beperkt de formele zorgorganisaties in het structureel blijven integreren van community health workers. Erkenning van het beroep is cruciaal in de empowerment, aangezien het beroepsstatuut ook een poortwachtersfunctie vervult. Aan de status zijn regels, voorschriften, verantwoordelijkheden verbonden, wat instrumentele beloningen kan opleveren (zoals toegang tot opleidingen of een fysieke werklocatie).

Wat *maatschappelijke erkenning* betreft, blijkt uit Hoofdstuk 4 dat het niet voor alle live-in migrant carers vanzelfsprekend is dat hun sociale omgeving hen erkent in hun werk. Dit gebrek aan erkenning is vaak het gevolg van negatieve connotaties die verbonden zijn aan het verlenen van inwonende zorg,

zoals het hebben van een laagbetaalde baan of het verrichten van huishoudelijk werk. Meer sociale erkenning, zoals erkenning voor het feit dat zij hun familie vaak vanop afstand financieel ondersteunen of meer waardering van de familieleden van de oudere voor wie zij zorgen, kan live-in migrant carers helpen trots te zijn op hun werk en zich erkend te voelen door de mensen om hen heen. Verder hechten de community health workers in Hoofdstuk 5 veel waarde aan de maatschappelijke erkenning die zij door hun werk van de leden van de gemeenschap krijgen. Dit maakt deel uit van een groter sociaal kapitaal, dat hen in staat stelt om veranderingen te bewerkstelligen en hun sociale positie te verbeteren.

Wat betreft *erkenning van ervaring en kennis*, laat dit proefschrift zien dat de meerderheid van de betrokken live-in migrant carers geen formele zorgkundige opleiding heeft gevolgd. Hoofdstuk 3 wijst er echter op dat deelnemers (zorgontvangers, uitzendbureaus en zorgverleners) geloven dat de live-in migrant carers de nodige vaardigheden hebben verworven door eerdere zorgervaringen met familieleden of beschikken over persoonlijke kwaliteiten en eigenschappen (bijvoorbeeld toegewijd of enthousiast zijn). Hoofdstuk 6 toont aan dat de kennis en vaardigheden van de community health workers worden erkend door het toepassen van strengths-based education (Lopez & Louis, 2009) in het werk-trainingsprogramma. Op deze manier kunnen hun competenties en sterke punten worden geïdentificeerd, erkend en bevestigd. Al te vaak worden vaardigheden van werkzoekenden immers niet erkend of onvoldoende benut (Schuster et al., 2013), waardoor ze als ondergekwalificeerd worden beschouwd ondanks hun potentieel voor het beroep.

### ONDERZOEKSDOELSTELLING 3: NAGAAN HOE ZORGORGANISATIES EMPOWERED KUNNEN WORDEN OM BETER IN TE SPELEN OP DE DIVERSE ZORGNODEN VAN OUDEREN

Dit proefschrift toont aan dat wederzijds leren tussen alternatieve zorgmedewerkers en zorgprofessionals van formele organisaties, en leren van tekortkomingen in het zorgaanbod, zorgorganisaties in staat kan stellen om beter tegemoet te komen aan diverse zorgnoden van ouderen.

Allereerst laat Hoofdstuk 6 zien dat wederzijds leren tussen alternatieve zorgwerkers en zorgprofessionals inhoudt dat kennis, ideeën en ervaringen worden uitgewisseld en dat men van elkaar leert. Wederzijds leren vraagt om een sterke betrokkenheid en inzet van zorgorganisaties. Om wederzijds leren mogelijk te maken, moet immers een volledig ondersteunende context worden gecreëerd. Daarom is het creëren van mogelijkheden voor community health workers om actief deel te nemen aan de zorgorganisatie essentieel, anders zal de overdracht van kennis van de community health worker naar de hele organisatie beperkt zijn. Dit vereist een investering in culturele competentie voor de hele organisatie, op verschillende niveaus van de organisatie en niet alleen voor de medewerkers die in rechtstreeks contact staan met ouderen. In Hoofdstuk 5 wordt gewezen op de behoefte van de community health worker in opleiding ervaringen kunnen uitwisselen en van elkaar kunnen leren. Voortbouwend op deze bevinding kunnen we concluderen dat zorgorganisaties een belangrijke rol kunnen spelen in mentoring.

Ten tweede, brengt Hoofdstuk 3 tekortkomingen in het formele zorgaanbod aan het licht, terwijl het ingaat op de motivaties van ouderen en hun families om een beroep te doen op live-in migrant carers. Formele diensten zijn vaak ofwel ontoereikend voor ouderen om thuis te kunnen blijven wonen (bijvoorbeeld door een gebrek aan 24-uurszorggarantie), ofwel beantwoorden ze niet aan hun noden en voorkeuren. Zorgorganisaties zouden van hun motivaties kunnen leren door hun diensten aan te passen aan de noden van ouderen (bijvoorbeeld ouderen in staat stellen de regie over hun zorg te behouden, persoonsgerichte en continue zorg verlenen). Daarnaast wordt in Hoofdstuk 6 aangegeven dat actieve betrokkenheid van een community health worker zorgorganisaties kan wijzen op tekortkomingen in hun aanbod en hen kan stimuleren om meer cultureel competent te werken. Het blijft echter moeilijk om een verandering in de diepe structuur van de zorgorganisatie te bewerkstelligen, wat betekent dat het zorgaanbod wordt ontwikkeld en aangepast aan de doelgroep en niet andersom.

### 3 | IMPLICATIES VOOR BELEID, PRAKTIJK EN TOEKOMSTIG ONDERZOEK

Op basis van de resultaten van dit proefschrift kunnen verschillende implicaties voor beleid, praktijk en toekomstig onderzoek worden gemaakt.

Op het gebied van beleid en praktijk, ten eerste, zouden alternatieve zorgverleners economisch, sociaal en politiek gewaardeerd moeten worden. Dit omvat een eerlijke verloning, aangezien onze bevindingen aantonen dat alternatieve zorgverleners vaak economisch verantwoordelijk zijn voor hun gezin. De maatschappelijke waardering van alternatieve zorgverleners wordt weerspiegeld in de lage status die aan hun werk wordt toegekend en in de perceptie van laaggeschoolde werknemers. Bovendien moeten alternatieve zorgverleners politiek worden gewaardeerd, aangezien politieke regelgeving de werk- en leefomstandigheden bepaalt. Voor live-in migrant carers zal een formele arbeidsstatuut om hun professionele status te erkennen en hen recht te geven op institutionele steun en instrumentele beloningen.

Ten tweede moet strengths-based education voor alternatieve zorgverleners worden georganiseerd. Op die manier worden eerder verworven vaardigheden erkend en versterkt. Maar al te vaak worden hun ervaringen en vaardigheden niet erkend en onvoldoende benut, ondanks hun grote potentieel.

Ten derde moet bij de ontwikkeling van beleid en praktijken voor alternatieve zorgverleners een intersectioneel levensloopperspectief worden gehanteerd. Dit maakt het mogelijk om rekening te houden met de complexe interacties tussen micro-, meso- en macrostructuur en het beoordelen van de gevolgen op de ervaringen van alternatieve zorgverleners.

Gebaseerd op dit proefschrift kunnen verschillende aanbevelingen voor toekomstig onderzoek worden gedaan. Ten eerste moet toekomstig onderzoek rekening houden met het belang van een vertrouwensrelatie met zowel de organisaties waarmee ze contact opnemen voor het werven van respondenten als met mogelijke deelnemers voordat ze een interview afnemen.

Ten tweede moet toekomstig onderzoek een faciliterende ruimte creëren waarin ervaringen kunnen worden gedeeld. Dit houdt in dat passende maatregelen moeten worden genomen wanneer online interviews worden afgenomen of wanneer interviews in een tweede taal worden afgenomen.

Ten derde wordt voorgesteld om in toekomstig onderzoek een multi-stakeholder perspectief te integreren. Een multi-stakeholder perspectief zal onderzoek toelaten om de verschillende perspectieven binnen een zorgverleningsrelatie te begrijpen. Dit zorgt voor een meer genuanceerd en omvattend begrip van interactionele systemen.

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Does the stigmatisation of older people with a migrant background constrain them from accessing care services?

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Does the stigmatisation of older people with a migrant background constrain them from accessing care services?

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Findings from the 'Culturally sensitive Care ambassadors - Valorizing talents' project.

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