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Long-term and palliative care at home: skill-mix innovations for enhanced responsiveness and satisfaction of patients and caregivers

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7.1 Introduction

Timely access to long-term care and palliative care that takes patients' individual choices into account has been an area of concern to policy-makers in many European countries. The majority of Europeans wish to receive long-term care in their homes for as long as possible (European Commission, 2007). They are often primarily cared for by their families and supported by health and social care professionals. Moving to a nursing home or a similar institution is the first preference of only approximately 10% of Europeans. As to palliative care, the majority of patients prefer to stay at home under the care of the regular health care providers with whom they often have longstanding relationships.

Hence, the policy focus in many countries is on strengthening its health and social care workforce as well as informal caregivers to ensure people can stay in their homes (OECD/EU, 2016). Similarly, the importance of the home care setting for persons with palliative care needs has increased as well. Therefore, this chapter focuses on skill-mix innovations in the ambulatory and in particular home care settings, and not on institutionalized care.

Although both long-term and palliative care are targeting people with functional limitations and the need for help with activities of daily living or with psychosocial needs, their underlying concepts are distinctly different. Long-term care at home aims to support people with limitations and their families' support (formal or informal) to live at home for as long as possible and as independently as possible. Typically,

this refers to self-management support, preventive and rehabilitative care, help with activities of daily living, such as bathing, dressing and getting in and out of bed, performed by a team of health professionals, including nursing and other professions, but mostly by family caregivers (Colombo et al., 2011).

Following the WHO definition, the concept of palliative care aims to improve the quality of life of patients and their families facing incurable, often life-threatening, illness, through the prevention and relief of suffering by means of early identification, assessment and treatment of pain and other problems (physical, psychosocial and spiritual) (World Health Organization, 2018a). According to the WHO, long-term and palliative care should be designed to provide high-quality care, in a way that is people-centred and consistent with their rights, fundamental freedoms and human dignity (World Health Organization, 2017).

In light of an increased demand due to a rising burden of noncommunicable diseases, ageing populations and changing family constellations (World Health Organization, 2018b), there are existing skill gaps in both areas of care. Reasons include a lack of skilled providers, poor work environments, limited career options and insufficient financing and payment of services. Additional skill gaps in long-term care include a lack of (sufficient time for) communication, self-management, support, social care, patient-centred services and limited choices as to people's preferred place of living. In palliative care, skill gaps are also frequent, due to a shortage of palliative-care specialists with skills in pain management for severe pain and end-of-life palliation. Other skill gaps include support for spiritual needs as well as addressing patients' individual needs and wishes during the phase of transition from acute care to palliative care and at the end-of-life.

Across Europe, several skill-mix changes in policy and practice have emerged in long-term care over the past decade, ranging from small-scale programmes to larger scale reforms. Two major trends can be observed: current and expected future workforce shortages that generate a need to attract more health professionals into providing long-term care of high quality; and interventions that specifically focus on skills enhancements to empower and support the people and their caregivers. As to palliative care, there are only a few skill-mix developments like in pilot programmes for palliative care teams with specialized skills in Belgium, Germany, the Netherlands and the United Kingdom.

This chapter aims to describe and analyse main skill-mix changes for patients receiving long-term and palliative care at home and their caregivers. In order to do so, a summary of the evidence on existing skill-mix innovations is given in the first section based on the overview of reviews (for the methodology, see Chapter 1), including evidence on their effectiveness in terms of health outcomes, resource use and professional outcomes. The second section shows trends in skill-mix innovations for both areas of care from a cross-country perspective.

7.2 Evidence on outcomes

The overview of reviews identified 17 systematic reviews (Box 1). Overall and especially in palliative care, the number of systematic reviews was relatively low when compared to those identified for the other Chapters.

Long-term care

Skill-mix interventions in long-term care

Interventions in long-term care comprised a broad range of skill-mix innovations (Table 7.1) of which the introduction of case management was the most prominent. Ten systematic reviews summarized the effects of case management for people requiring long-term care at home and

Box 7.1 Overview of the evidence on long-term and palliative care

Number of reviews: 17 systematic reviews covering a total of 286 studies were identified, with six systematic reviews related to palliative care and 11 related to long-term care.

Country coverage: The majority of studies were conducted in the USA and in Europe, especially in the United Kingdom. Other countries were Australia, Belgium, Canada, China, Denmark, Finland, France, Germany, Hong Kong, India, Israel, Italy, Japan, Luxembourg, the Netherlands, New Zealand, Norway, Pakistan, Poland, Singapore, Spain, Sweden, Taiwan, Tanzania, Turkey.

Methods: Overall, several reviews were of comparatively low quality. Although there were three Cochrane reviews included, one did not include any suitable study. In sum, five meta-analyses were performed.

Table 7.1 Evidence for skill-mix interventions in long-term care from the overview of reviews

Skill-mix interventions		Outcomes				
Content of interventions and skill-mix changes	Profession(s) in intervention and in comparator group	Population	Countries (number)	Patient-related outcomes	Health-system-related outcomes	Profession-/Informal caregiver-specific outcomes
Case management in the community						
<i>(i) For people with dementia and their caregivers [1–8]</i>						
Case management interventions for people with dementia and their caregivers, including case identification, counselling, coordinating, multidimensional assessment, monitoring, educating	Intervention: case managers with advanced training [1, 4, 6] and background in nursing, social work, psychology, among others Comparison: not reported	People with dementia living at home and their caregivers	Europe, USA among others (not fully reported, but most studies were conducted in the USA (>60) and in Europe, especially in the United Kingdom (>25)	<ul style="list-style-type: none"> • No effects on mortality [1–3, 6, 7] • Mostly no effects on depressive symptoms [1–4, 6], only two RCTs showed positive effects [3] • Mostly no effects on functional status [1–3, 6], two RCTs [3] showed positive effects • No effects on cognition [1–4, 6] • No effects on quality of life [3–6], positive effects were shown in two studies only [3, 7] • No effects on ADL [2, 4] 	<ul style="list-style-type: none"> • Most evidence on cost-effectiveness showed no effects [2, 3, 5, 6, 8] • Mixed evidence on ED-use with two RCTs showing positive and three RCTs showing no effects [2, 3, 8] • No evidence of effects on hospitalization-rates (>10 RCTs) [1–3, 6–8], only two RCTs showed intermediate effects [3] • Significant positive effect on length of hospital stay (two RCTs) [3] and reduction of days per month in a residential home or hospital unit at 6 months (one RCT) and at 12 months (one RCT) [6] 	<p>Professionals</p> <ul style="list-style-type: none"> • Improved satisfaction (two RCTs) [2, 3] <p>Informal caregivers</p> <ul style="list-style-type: none"> • Greater satisfaction with social support and a decrease in symptoms of depression (one RCT) [5] • Significantly improved dementia-guideline adherence and/or medication management (seven RCTs) [2–4]

- Significant reduction of embarrassment, isolation and improved coping with memory problems or diagnosis of dementia, with additional effects for people with more severe impairment ($n = 1$) [2]
- Statistically significant improvement in patients' access to services ($n = 1$) [7]
- Modestly statistically significant improvements at 18 months in the intensity of behavioural problems ($n = 1$) [7]
- Modestly higher compliance with guideline recommendations ($n = 1$) [7]
- No differences in time to institutionalization in a residential home (five RCTs), only one RCT showed a significant impact [8]
- Many studies within the reviews showed significant positive effects on institutionalization rates ($n = 19$) [1–3, 6], but more studies showed no effects ($n = 42$) [1–3, 6–8]; a meta-analysis of 16 RCTs revealed a significant positive effect after stratification for time to follow-up less than 18 months [8]

Table 7.1 (cont.)

Skill-mix interventions		Outcomes				
Content of interventions and skill-mix changes	Profession(s) in intervention and in comparator group	Population	Countries (number)	Patient-related outcomes	Health-system-related outcomes	Profession-/Informal caregiver-specific outcomes
Case management in the community						
<i>(ii) For older adults and their caregivers [9, 10]</i>						
Case management interventions to support informal caregivers of older adults, including assessment, planning, coordinating, monitoring and counselling	Intervention: Case managers with various backgrounds, research assistants, nurses, dementia family nurse care coordinator Comparison: not reported	Informal caregivers of adults aged 65 or older	FI (3), HK (1), ISR (1), IT (1), NL (1), UK (1), US (14)	<ul style="list-style-type: none"> • Improvements in emotional health ($n = 1$) [9] • Lower depression scores after 6 months ($n = 2$), but mixed results after 12 months [9] and no effect in psychiatric symptoms and associated behavioural problems ($n = 2$) [10] • No effects on quality of life ($n = 1$) [9] • Significantly improved health or well-being across different measures, such as self-perceived life satisfaction, morale, depression, mastery, and personal health status ($n = 5$) [10] 	<ul style="list-style-type: none"> • Decreases in municipal care costs per family per year in Finland ($n = 1$) [9] • Significant reductions of admissions to long-term institutions in first ($n = 1$) and 18th month of intervention ($n = 1$), but no differences after 24 months ($n = 2$) [9] 	Informal caregiver <ul style="list-style-type: none"> • No improvements in family caregivers emotional health, quality of life, sense of competence and mixed results regarding depressive symptoms ($n = 2$) [9] • Improved well-being ($n = 1$) vs no effects ($n = 4$) [10]

- Mixed results regarding functional status ($n = 4$ with positive, of which one only showed those effects in the long term rather than the short term and $n = 4$ with no or no clear effects) [9, 10]
 - Significantly less pain and dyspnoea during the 12-month follow-up period ($n = 1$) while another study showed no difference in patients' health status [10]
 - Mixed effects on patient satisfaction ($n = 5$) [9, 10]
 - Significant effect on mortality ($n = 2$) vs no significant intervention-control group differences ($n = 5$) [10]
 - Decreased unmet service needs ($n = 3$) [10]
- Mixed results on caregivers' stress or burden ($n = 5$): significant improvements in burden of caregiver ($n = 1$), significant reduced stress or burden ($n = 2$) vs no effect ($n = 2$) [10]
 - Improved caregiver satisfaction ($n = 2$) [9, 10] vs no effects ($n = 1$) [9]

Table 7.1 (cont.)

Skill-mix interventions		Outcomes					
Content of interventions and skill-mix changes	Profession(s) in intervention and in comparator group	Population	Countries (number)	Patient-related outcomes		Health-system-related outcomes	Profession-/Informal caregiver-specific outcomes
				Multidisciplinary team approach for the management of Parkinson [11]			
Multidisciplinary team approach, including group education activities specific to Parkinson's disease and individualized rehabilitation	Intervention: nurse, physical therapist, occupational therapist, speech therapist, dietician, neurologist, psychologist Comparison: not specified, but likely GPs or neurologist	Patients with Parkinson's disease	Japan (1), UK (1)	<ul style="list-style-type: none"> • Significant improvement in Parkinson's disease-related scores and patient mood ($n = 1$) • Improvements in health-related quality of life (e.g. 37% improvement), various function and mobility scores • Significant improvement in depression scores, voice articulation and speech ($n = 1$) 			<ul style="list-style-type: none"> • Informal caregiver mood did not significantly change

Abbreviations: ADL/EADL: activities of daily living/extended ADL; ED: emergency department; ER: emergency room; GP: general practitioner; IADL: instrumental ADL; MMSE: Mini-Mental State Examination; RCT: randomized controlled trial.

Country abbreviations: AU: Australia; FI: Finland; HK: Hong Kong; ISR: Israel; IT: Italy; NL: the Netherlands; UK: the United Kingdom, USA: the United States of America.

Sources: [1] Backhouse et al. (2017); [2] Goeman, Renehan & Koch (2016); [3] Khanassov, Vedel & Pluye (2014); [4] Khanassov & Vedel (2016); [5] Pimouguet, Lavaud & Dartiques (2010); [6] Reilly et al. (2015); [7] Somme et al. (2012); [8] Tam-Tham et al. (2013); [9] Berthelsen & Kristensson (2015); [10] You et al. 2012; [11] Prizer & Browner (2012).

their caregivers (Backhouse et al., 2017; Berthelsen & Kristensson, 2015; Goeman, Renehan & Koch, 2016; Khanassov, Vedel & Pluye, 2014; Khanassov & Vedel, 2016; Pimouguet, Lavaud & Dartigues, 2010; Reilly et al., 2015; Somme et al., 2012; Tam-Tham et al., 2013; You et al., 2012). This involved programmes integrating case managers into health care services for people specifically with dementia and their caregivers – covered by eight reviews (Backhouse et al., 2017; Goeman, Renehan & Koch, 2016; Khanassov, Vedel & Pluye, 2014; Khanassov & Vedel, 2016; Pimouguet, Lavaud & Dartigues, 2010; Reilly et al., 2015), and programmes targeting older patients with various conditions (including dementia) and their caregivers by introducing a case manager function, as in two reviews (Berthelsen & Kristensson, 2015; You et al., 2012). Regardless of the target group, the new tasks and skills covered by case management targeted various elements of care, ranging from counselling and coordinating care to assessing needs, planning care and support systems, monitoring and educating informal caregivers. Case managers had various backgrounds, in nursing, social work and psychology.

For people with Parkinson's disease, one review (Prizer & Browner, 2012) analysed a multidisciplinary team approach for the management of the condition. It included group education activities specific to Parkinson's disease and individualized rehabilitation. In this case, the multidisciplinary teams were composed of nurses, physical therapists, speech therapists, dieticians, neurologists and psychologists and were compared with usual care by GPs or neurologists. No example of skill-mix innovations involving new technologies or eHealth was identified.

Evidence on outcomes

Case management interventions for people with dementia and their caregivers were shown to reduce feelings of embarrassment and isolation, and to improve coping with memory problems or diagnosis of dementia, with additional effects for people with more severe impairment (one RCT) (Goeman, Renehan & Koch, 2016). The intensity of behavioural problems at 18 months follow up (one RCT) and adherence to guideline recommendations (one RCT) were also shown to be improved by introducing case management (Somme et al., 2012). Furthermore, patients' access to services was significantly improved compared with standard care (Somme et al., 2012). In terms of other patient-related outcomes, the majority of studies showed no impact of case management

interventions, for example, regarding depressive symptoms (Backhouse et al., 2017; Goeman, Renehan & Koch, 2016; Khanassov, Vedel & Pluye, 2014; Khanassov & Vedel, 2016; Reilly et al., 2015), functional status (Backhouse et al., 2017; Goeman, Renehan & Koch, 2016; Khanassov, Vedel & Pluye, 2014; Reilly et al., 2015) and quality of life (Khanassov, Vedel & Pluye, 2014; Khanassov & Vedel, 2016; Pimouguet, Lavaud & Dartigues, 2010; Reilly et al., 2015; Somme et al., 2012). No effects were shown on mortality (Backhouse et al., 2017; Goeman, Renehan & Koch, 2016; Khanassov, Vedel & Pluye, 2014; Reilly et al., 2015; Somme et al., 2012), cognition (Backhouse et al., 2017; Goeman, Renehan & Koch, 2016; Khanassov, Vedel & Pluye, 2014; Khanassov & Vedel, 2016; Reilly et al., 2015), and activities of daily living (Goeman, Renehan & Koch, 2016; Khanassov & Vedel, 2016). In terms of health-system-related outcomes, the evidence for effects in the community was mixed. Significant positive effects were shown on length of hospital stay (two RCTs, Khanassov, Vedel & Pluye, 2014) and on the number of days per month in a residential home or hospital unit at 6 months (one RCT) and at 12 months (one RCT, Reilly et al., 2015). Most studies analysing costs or cost-effectiveness showed no effects (Goeman, Renehan & Koch, 2016; Khanassov, Vedel & Pluye, 2014; Pimouguet, Lavaud & Dartigues, 2010; Reilly et al., 2015; Tam-Tham et al., 2013). Several studies included in the reviews showed significantly reduced institutionalization rates ($n = 19$, Backhouse et al., 2017; Goeman, Renehan & Koch, 2016; Khanassov, Vedel & Pluye, 2014; Reilly et al., 2015), but more studies showed no effects ($n > 30$, Backhouse et al., 2017; Goeman, Renehan & Koch, 2016; Khanassov, Vedel & Pluye, 2014; Reilly et al., 2015; Somme et al., 2012; Tam-Tham et al., 2013). Mixed results were also shown for emergency department visits (Goeman, Renehan & Koch, 2016; Khanassov, Vedel & Pluye, 2014; Tam-Tham et al., 2013), for time to institutionalization to a residential home (Tam-Tham et al., 2013) and for hospitalization rates. For the latter, several RCTs showed no effects (Backhouse et al., 2017; Goeman, Renehan & Koch, 2016; Khanassov, Vedel & Pluye, 2014; Reilly et al., 2015; Somme et al., 2012; Tam-Tham et al., 2013) and only two RCTs reported intermediate effects (Khanassov, Vedel & Pluye, 2014). A meta-analysis of 16 RCTs revealed a significant positive effect after stratification for time to follow-up less than 18 months (Tam-Tham et al., 2013). In terms of profession-specific outcomes, the reviews found significantly improved guideline adherence and medication

management (Goeman, Renehan & Koch, 2016; Khanassov, Vedel & Pluye, 2014; Khanassov & Vedel, 2016). In a few studies, satisfaction was shown to be improved for both professionals (Goeman, Renehan & Koch, 2016; Khanassov, Vedel & Pluye, 2014) and informal caregivers (Pimouguet, Lavaud & Dartigues, 2010). Moreover, receiving support from a case manager resulted in a decrease in depressive symptoms of caregivers (one RCT, Pimouguet, Lavaud & Dartigues, 2010).

Providing case management interventions to support older adults and their family caregivers (Berthelsen & Kristensson, 2015; You et al., 2012) was shown to improve patients' emotional health ($n = 1$) and depression 6 months after intervention ($n = 2$). However, after 12 months, results for depression were mixed (Berthelsen & Kristensson, 2015). Mixed results were also shown for functional status with four studies reporting positive and negative effects (Berthelsen & Kristensson, 2015; You et al., 2012). One of the studies only showed positive effects on functional status in the long rather than the short term (You et al., 2012). Furthermore, one study showed no effects on quality of life and the results of five studies on effectiveness of case management for older adults and their caregivers were inconclusive in terms of patient satisfaction (Berthelsen & Kristensson, 2015; You et al., 2012). The results on mortality were not clear either with two studies reporting significant positive effects and five studies reporting no significant differences. However, providing case management was shown to decrease unmet needs compared with standard care ($n = 3$, You et al., 2012). In terms of health system outcomes, some positive effects were shown, for example, decreased municipal care costs per family per year in Finland ($n = 1$) and significantly reduced admissions to long-term institutions in first ($n = 1$) and 18th month of intervention ($n = 1$). However, there were no differences after 24 months ($n = 2$). One study included in the review showed higher overall caregiver satisfaction, but two studies showed no improvements in emotional health, quality of life, sense of competence and mixed results in terms of caregivers' depression.

For people suffering from Parkinson's disease, integrating a multidisciplinary team approach in health care (Prizer & Browner, 2012) was shown to significantly improve Parkinson's disease-related scores and patient mood ($n = 1$), health-related quality of life as well as depression scores, voice articulation and speech ($n = 1$). Caregiver mood was not shown to be improved and no health-system-related outcomes were assessed.

Palliative care

Skill-mix interventions in palliative care

Generally, fewer skill-mix developments in palliative care were identified in the literature compared with long-term care, and as a consequence the evidence on their effectiveness is limited. Nevertheless, skill-mix interventions directed at patients in palliative situations and their caregivers included various models and were assessed by six reviews (Table 7.2).

A Cochrane review that aimed to analyse the effects of a systematic and organized approach to collaboration with a multidisciplinary team involving at least two professions from different disciplines and targeting adult home hospice patients could not identify any study that met the inclusion criteria (Joseph et al., 2016).

Another Cochrane review (Shepperd et al., 2016) assessed the effectiveness of any home-based end-of-life care interventions, including consultation, multidisciplinary care coordination, physiotherapy, informal help, nutrition and social care, and (if needed) 24-hour care, that provides active treatment for continuous periods of time by health care professionals, for example, specialist palliative-care nurses, qualified nurses, family physicians, palliative-care consultants, physiotherapists, occupational therapists, nutritionists and social care workers. In the majority of studies, the interventions were carried out by a multidisciplinary team.

Dy et al. (2013) analysed the effects of interventions that focus on continuity, coordination and transition, including (i) involvement of the patient, the family or the caregiver, for example, through education; (ii) coordination with an additional provider to provide care; (iii) conducting care plans or (iv) introducing palliative-care specialists. Professions involved in the interventions were palliative-care specialist, nurse case managers, physicians, GP, nurse specialist, social workers, case coordinators and case managers.

Furthermore, Carmont et al. (2018) analysed interventions designed to engage GPs with special secondary services in integrated palliative care, including shared consultations or case conferences. Professions in the intervention were GPs and at least one other profession, for example, nurses, medical specialists or allied health professionals.

Another skill-mix innovation in palliative care was pain medication management educational interventions for family caregivers of patients with advanced cancer (Latter et al., 2016). This included face-to-face

Table 7.2 Evidence from the overview of reviews for skill-mix innovations in palliative care

Skill-mix interventions				Outcomes		
Content of interventions and skill-mix changes	Profession(s) in intervention and in comparator group	Population	Countries	Patient-related outcomes	Health-system-related outcomes	Profession-/Informal caregiver-specific outcomes
Interventions mainly focusing on patients						
<i>(i) Integrated palliative care involving GPs [1]</i>						
Interventions designed to engage GPs with specialist secondary services in integrated palliative care, e.g. including shared consultations or case conferences	Intervention: GPs and at least one other profession, e.g. nurses, medical specialists, allied health professionals Comparison: GPs only, specialists only	Patients aged 18 years or older in a palliative situation receiving services through their GP, specialist hospital services or an integrated model of care	AU (4), CA (2), DK (1), NZ (1), NL (1), UK (3) and 5 with no country reported	<ul style="list-style-type: none"> • Significant improvements in patient functional status ($n = 2$) • Improved pain management, symptom control and safety for patients and family: from both GP ($n = 1$) and patient perspective ($n = 2$) • No effects on quality of life or symptom burden ($n = 2$) 	<ul style="list-style-type: none"> • Significant decrease in number of hospital admissions ($n = 3$) • Case conferences and shared care were both effective in reducing the length of hospital stay ($n = 2$) 	<p>Professionals</p> <ul style="list-style-type: none"> • Strengthening of service relationships, improved interprofessional communication and improvements in professional developments ($n = 2$)

Table 7.2 (cont.)

Skill-mix interventions				Outcomes		
Content of interventions and skill-mix changes	Profession(s) in intervention and in comparator group	Population	Countries	Patient-related outcomes	Health-system-related outcomes	Profession-/Informal caregiver-specific outcomes
Interventions mainly focusing on patients						
<i>(ii) Structured interdisciplinary collaboration [2]</i>						
Any systematic and organized approach to collaboration leading to the attainment of specific goals involving rules and guidelines	Intervention: at least two professions from different disciplines (not fully described) Comparison: not reported	Adult home hospice patients			no study met the inclusion criteria	
<i>(iii) Home-based end-of-life care interventions [3]</i>						
Any home-based end-of-life care intervention that provides active treatment for continuous periods of time by health care	Intervention: Specialist palliative-care nurses, qualified nurses, family physicians, palliative-care consultants, physiotherapist,	People, aged 18 years and over, who are at the end of life and require terminal care. Some had	USA (2), UK (1), Norway (1)	<ul style="list-style-type: none"> Significant increased likelihood of dying at home compared with usual care ($n = 3$ RCTs) 	<ul style="list-style-type: none"> Significant reduction in health care costs ranging between 18% and 30% in the USA ($n = 2$ RCTs) 	Informal caregivers <ul style="list-style-type: none"> Higher caregivers' satisfaction only at 1-month, but not at 6-month, follow-up and caregivers of participants who had survived more than 30 days showed a decrease in psychological well-being (one RCT)

professionals in the patient's home for patients who would otherwise require hospital or hospice inpatient end-of-life care. Including: consultation, multidisciplinary care coordination, physiotherapy, informal help, nutrition and social care, if needed 24-hour care

occupational therapists, nutritionists, and social care workers; in three-quarters of studies working as a multidisciplinary team
Comparison: not reported

a diagnosis of chronic disease (like heart failure, obstructive pulmonary disease, cancer)

- Little difference to functional status (measured by the Barthel Index), psychological well-being, or cognitive status ($n = 1$ RCT)
- Slightly improved patient satisfaction at follow up after 1 month, but not after 6 months ($n = 2$ RCTs)
- Unclear effects on 6-month mortality ($n = 1$ RCT)
- Mixed results on admission to hospital ($n = 4$ RCTs)
- Little or no effect on caregiver bereavement response 6 months following death (one RCT)

Table 7.2 (cont.)

Skill-mix interventions				Outcomes		
Content of interventions and skill-mix changes	Profession(s) in intervention and in comparator group	Population	Countries	Patient-related outcomes	Health-system-related outcomes	Profession-/Informal caregiver-specific outcomes
Interventions mainly focusing on patients						
<i>(iv) Interventions that focus on continuity, coordination and transition [4]*</i>						
Interventions that focus on (i) patient/family/caregiver involvement (e.g. through education); (ii) coordination with an additional provider to provide care; (iii) conducting care plans or (iv) introducing palliative-care specialists	Intervention: palliative-care specialist, nurse case managers, physicians, GP, nurse specialist, social workers, case coordinators, case managers Comparison: not reported	Adults with mixed illnesses or cancer patients. Those unlikely to be cured, recover or stabilize	Not reported	<ul style="list-style-type: none"> • Significant effects ($n = 3$) vs no effects on quality of life ($n = 6$) • Significant improved satisfaction ($n = 6$) vs no effects ($n = 1$) 	<ul style="list-style-type: none"> • Only 5 out of 16 studies evaluating health care utilization, e.g. in terms of hospital admission and length of stay, found significant effects • No significant effects for most of the studies in each intervention component. 	Informal caregivers <ul style="list-style-type: none"> • Significant effects on caregiver satisfaction ($n = 4$) vs no effects ($n = 2$) • No effects on caregiver burden ($n = 3$) • Significant quality of life improvements for caregivers ($n = 1$)

Interventions mainly focusing mainly on family caregivers

(i) Pain medication management for family caregivers [5]

Pain medication management educational interventions for family caregivers of patients with advanced cancer, including face-to-face education or training sessions, opportunities for questions and discussion, and follow-up contacts for reinforcement or further coaching

Intervention: nurses, psychologists, researcher
Comparison: not reported

Caregivers of patients with advanced cancer

NO (1), UK (1), USA (5), Taiwan (1)

- Significantly higher medication adherence at 2 and 4 weeks ($n = 1$ RCT) vs no reported data in a single-group pilot study
- Significantly reduced pain ($n = 2$) vs no effects on significant effect on pain ($n = 4$)

Informal caregivers

- Significant effects ($n = 3$) vs no effects on caregivers' knowledge and beliefs about pain management ($n = 4$)
- Significant improvements on self-efficacy/perceived control over pain (one RCT)

Table 7.2 (cont.)

Skill-mix interventions				Outcomes		
Content of interventions and skill-mix changes	Profession(s) in intervention and in comparator group	Population	Countries	Patient-related outcomes	Health-system-related outcomes	Profession-/Informal caregiver-specific outcomes
Interventions mainly focusing mainly on family caregivers						
<i>(ii) Psychosocially and/or psycho-educationally based interventions for family caregivers [6]</i>						
Psychosocially and/or psycho-educationally based interventions for family caregivers including psychoeducation, psychosocial support, caregivers coping, symptom management, sleep promotion and family meetings	Intervention: not reported Comparison: not reported	Adult family caregivers of palliative care patients	Majority of the 14 studies were conducted in industrial countries			Informal caregivers <ul style="list-style-type: none"> • Positive effects on depression levels of caregivers of patients with Alzheimer’s disease ($n = 1$) • Improvements in sleep quality and depression in the caregiver ($n = 1$) • No significant benefit to caregivers’ psychosocial health or well-being ($n = 1$) • Significant favourable effects of a psycho-educational programme on caregivers’ perceptions of positive elements of their role ($n = 1$); on family caregivers’ quality of life ($n = 1$) as well as the perceived burden of patients’ symptoms and their perceived burden of care tasks ($n = 1$) vs no significant benefit to caregivers through a separate psychosocial support intervention ($n = 1$)

- Significant positive effects on caregivers' preparedness, competence, reward ratings ($n = 1$)
- Reduction of unmet needs ($n = 2$)
- Positive caregivers' perception of the intervention ($n = 3$)
- Significant increased caregivers' levels of comfort, closure and satisfaction ($n = 1$)
- Psychological benefits for caregivers ($n = 1$)
- Significantly higher ratings of caregivers' self-efficacy for helping patients to control pain and other symptoms ($n = 1$)

Abbreviations: ED: emergency department; ER: emergency room; GP: general practitioner; RCT: randomized controlled trial.

Country abbreviations: AU: Australia; CA: Canada; DK: Denmark; NL: the Netherlands; NO: Norway; NZ: New Zealand; UK: the United Kingdom; USA: the United States of America.

Notes: * Evidence for different intervention components on patient/family/caregiver outcomes: improvement for patient or family-related outcomes with family/patient involvement (6/9); additional patient assessment was significantly improved in nine out of twelve studies; coordination showed significant improvements in six out of nine studies on either quality of life or satisfaction; improvements for palliative-care specialist involvement in three out of five studies.

Sources: [1] Carmont et al. (2018); [2] Joseph et al. (2016); [3] Shepperd et al. (2016); [4] Dy et al. (2013); [5] Latter et al. (2016); [6] Hudson, Remedios & Thomas (2010).

education or training sessions, typically supported by written and other resources, opportunities for questions and discussion, and follow-up contacts for reinforcement or further coaching. Professions covered in those interventions were nurses, psychologists and researchers.

Hudson, Remedios & Thomas (2010) assessed the effectiveness of psychosocially and/or psycho-educationally based interventions for family caregivers including psychoeducation, psychosocial support, caregivers' coping, symptom management, sleep promotion and family meetings. Professions involved in the interventions were not reported.

Examples of skill-mix innovations and new technologies/eHealth were not identified in the systematic reviews.

Evidence on outcomes

Interventions designed to engage GPs in integrated palliative care (Carmont et al., 2018) were shown to significantly improve patient functional status ($n = 2$), but to have no effects on patients' quality of life or symptom burden ($n = 2$). Results from qualitative studies included in the same review suggest improved pain management, symptom control as well as increased safety for patients and family from both GP ($n = 1$) and patient perspective ($n = 2$). In terms of health-system-related outcomes, the studies showed a significant decrease in the number of hospital admissions. Furthermore, case conferences and shared care were both effective in reducing the length of hospital stay. Outcomes related to professions were shown to be improved in terms of strengthened service relationships, a better interprofessional communication and professional development ($n = 2$).

In their Cochrane Review, Shepperd et al. (2016) showed that palliative patients receiving home-based end-of-life care were more likely to die at home than patients receiving usual care ($n = 3$ RCTs). In two RCTs, patient satisfaction was also shown to be slightly improved at follow up after 1 month. However, there was no difference after 6 months. Little effect on functional status (measured by the Barthel Index), psychological well-being or cognitive status ($n = 1$ RCT) was shown. The effects on 6-month mortality were unclear ($n = 1$ RCT). In terms of outcomes related to the health care system a significant reduction in health care cost between 18% and 30% in the USA was reported in two RCTs. But results on admission to hospital were mixed ($n = 4$ RCTs). Effects on informal caregiver outcomes are uncertain: Differences

in caregivers' satisfaction were only reported at 1-month follow up, but not at 6-months. Furthermore, caregivers of participants who had survived more than 30 days showed a decrease in psychological well-being ($n = 1$ RCT). In terms of caregiver bereavement response little or no effect was shown 6 months following death ($n = 1$ RCT).

Interventions that focus on continuity, coordination and transition were shown to significantly improve satisfaction in six studies included in the systematic review from Dy et al. (2013). Only one study showed no effects. Effects on quality of life were more unclear with three studies showing positive effects and six studies showing no differences. The caregivers' quality of life was reported to be significantly improved ($n = 1$) while no effects on their burden were shown in three studies. In terms of caregiver satisfaction, the results were mixed. A significant positive effect on caregiver satisfaction was shown in four studies and no difference was reported in two studies. Evidence on effects of single intervention components revealed improvements for patient- or family-related outcomes with family/patient involvement in six of nine studies. Using additional patient assessment was found to be significantly improved in nine out of twelve studies. Furthermore, providing coordination showed significant improvements in six out of nine studies on either quality of life or satisfaction. Improvements for palliative-care specialist involvement were shown in three out of five studies. In terms of outcomes related to the health care system, most studies showed no effects of single components. Only 5 out of 16 studies evaluating health care utilization, for example in terms of hospital admission and length of stay, found significant effects.

Providing psychosocially and/or psycho-educationally based interventions for family caregivers resulted in positive effects on caregivers' depression ($n = 2$), on sleep quality ($n = 1$), as well as on their preparedness, competence and reward ratings ($n = 1$). Furthermore, a significantly increased level of comfort, closure and satisfaction was reported ($n = 1$). Another study showed significantly higher ratings of caregivers' self-efficacy for helping patients to control pain and other symptoms ($n = 1$). It was also reported that implementing such interventions resulted in a reduction of unmet needs ($n = 2$). In general, caregivers' perception of the intervention was shown to be positive ($n = 3$). A psycho-educational programme was shown to have significant favourable effects on caregivers' perceptions of positive elements of their role ($n = 1$) and on family caregivers' quality of life ($n = 1$). Effects on perceived burden

of patients' symptoms and their perceived burden of care tasks were inconclusive with one study showing significant positive effects and one study showing no significant benefit to caregivers while receiving a separate psychosocial support intervention. Effects on psychological benefits for caregivers are also unclear with one study showing positive effects and another study showing no significant benefit to caregivers' psychosocial health or well-being. Hudson, Remedios & Thomas (2010) did not assess outcomes related to the patient or the health system.

In another review that aimed to analyse the effects of interventions focused on caregivers, providing pain medication management interventions to family caregivers of patients with advanced cancer (Latter et al., 2016) was shown to significantly improve medication adherence in one RCT. Mixed effects were found on pain and on caregivers' knowledge and beliefs about pain, although one study included in the review reported significant improvements in self-efficacy and perceived control over pain. Analyses are missing on health-system-related outcomes and outcomes related to professionals.

Education and training of the professions involved in the skill-mix changes

Most systematic reviews did not report details on the education and training of the professions covered in the studies. Only three studies on long-term care described the training in the skill-mix intervention groups, but not always in a systematic manner and they lacked details on the content, length and curricula. These studies reported that case managers received a specific advanced training (Backhouse et al., 2017; Khanassov & Vedel, 2016; Reilly et al., 2015). For example, Khanassov & Vedel (2016) described training of case managers in geriatrics/geronto-psychiatry, communication with patients and their caregivers and dementia home care. Another review reported that case managers with advanced training in six RCTs received training ranging from a 1-week intensive course to advanced practice education (3½ years) and additional special education in dementia care with a duration of 1 year (Reilly et al., 2015).

Limitations and strength of evidence

A strength of this chapter is the comprehensive definition of skill-mix including not only all health professions but also explicitly including informal caregivers for people requiring long-term care and/or palliative

care. However, several limitations exist. First, the number of reviews identified was low, particularly for palliative care. Second, the systematic reviews on long-term care presented an uneven coverage of conditions. Several systematic reviews exist for people with Alzheimer's disease. For people with other conditions, such as Parkinson's disease, the number of reviews was very low or non-existent, for example, for other functional impairments or mental health. Three Cochrane reviews were included of which two focused on palliative care. However, one of them did not identify studies that met the inclusion criteria. In sum, five meta-analyses were performed. The transferability of the findings across countries is limited as most studies were from the USA and there were only a small number of studies from Europe. Evidence on profession-related effects was limited across all reviews. The generally low quality of the evidence and heterogeneity of the interventions require cautious interpretation of the findings.

Summary of the evidence

The evidence suggests that case management for people with long-term care needs may result in some, albeit generally few, improvements for patients and their caregivers. For people with dementia, introducing case manager roles may be associated with reduced feelings of isolation and embarrassment of the condition, and may improve coping with memory problems. Furthermore, evidence provides indications that patients' access to services and their compliance with guideline recommendations is improved. On other outcomes, such as functional status, depression or mortality, the evidence was either inconclusive or showed no effect. The reason may be that improvements for this target group are more difficult to achieve and to measure than for other conditions, an issue that should be investigated in future research.

For case management provided to older people living at home and their caregivers, results were different; for example, regarding informal caregivers and also in terms of health-system-related outcomes, where the evidence suggests that municipal costs may decrease after implementing case management interventions. Interestingly, and similar to dementia-specific case management interventions, a decrease in unmet service need was found.

For patients with Parkinson's disease, introducing multidisciplinary teams may improve quality of life and other outcomes. Generally, the evidence was limited in terms of quantity and quality of effects.

On palliative care, the number of reviews covering people in their homes was low, but evidence suggests that home-based end-of-life care interventions may result in an increased likelihood of dying at home. Moreover, the majority of studies that analysed effects on patient satisfaction showed a positive impact. They also found improved caregiver satisfaction and a lower caregiver burden after introducing various skill-mix changes as well as a decrease in unmet needs. For patients' quality of life and pain management the results were inconclusive. There is also some evidence of enhanced efficiency gains for health systems (for example, decrease in hospital admissions, reduced length of stay) and improved profession-specific outcomes (such as strengthened communication and service relationships) with increased collaboration across disciplines in palliative care.

Given the rapid increase in the number of people requiring long-term and palliative care over the past decade in Europe, and future projections, there is an urgent need for more and high-quality research on skill-mix requirements to provide quality care for patients in their homes, also including new technologies/eHealth.

7.3 Skill-mix innovations and reforms: overview of trends across Europe

Long-term care

Skill-mix changes and reforms

Most debates on the workforce in long-term care at home have focused on increasing the quantity of staff, with little attention paid to their skill-mix. Nevertheless, two major trends can be noted. First, current and expected future workforce shortages generate a need to attract more health professionals in long-term care (De Klaver et al., 2013). To attract more health professionals, such as nurses or lay workers in long-term care, job opportunities are created for long-term unemployed, migrant populations or adults with disabilities (De Klaver et al., 2013). At the same time, especially as better-qualified staff are a scarce resource, specific tasks from better-qualified staff are re-allocated towards less-qualified staff. Second, due to the complexity in care and in delivery of coherent, high-quality care, a few European countries, for example, Austria, Bulgaria and Serbia, implemented new roles for better-qualified staff (specialized in the care of older adults) or introduced new

(multidisciplinary) teams or a new modality of teamwork to improve long-term care.

Examples specific to long-term care of creating job opportunities for unemployed or migrant populations are the introduction of geriatric home care assistants (Geronto service) in Serbia (Milicevic, forthcoming) (see Box 7.2), the 24-hour care workers in Austria (Habimana et al., forthcoming), or the assistants for disabled people in Bulgaria (De Klaver et al., 2013). Examples of task allocation are physicians that are partially substituted by registered nurses or registered nurses that are partially substituted by less-qualified assistants. In the Netherlands, nurse practitioners, physician assistants and registered nurses are legally allowed to partially substitute GPs or nursing home physicians. However, because of a shortage of nurses, this does not happen on a regular basis (Lovink et al., 2018). In Belgium, health care assistants were introduced, providing basic care under nurse supervision (Sermeus, forthcoming). In Austria, Belgium and Denmark, informal caregivers (often family members) receive (psychological) support (Burau, Doessing & Kuhlmann, forthcoming; Habimana et al., forthcoming; Sermeus, forthcoming). Supporting and investing in informal caregivers might be a solution to compensate for shortages in formal caregivers, as informal caregivers can take over parts of the tasks of formal caregivers.

Box 7.2 Home care assistants – Geronto service in Serbia (Milicevic forthcoming)

Over the past two decades a home care community-based care service for older people has been implemented in Serbia. The so-called Geronto service was introduced in 2007 as a 6-month project within the Poverty Reduction Strategy of the Serbian government with the aim of improving the economic and social position of socially vulnerable people such as older people and those with chronic illness and disabilities, by providing them with housekeeping and household maintenance services, personal hygiene services, preventive health care services, and psychosocial support services.

Contextual drivers

Serbia has one of the largest older population segments in the world (Sevo et al., 2009), so has a rising need for medical and social care and a reduced offer of informal care by family members. In order to implement

Box 7.2 (cont.)

a Geronto service, an accredited training programme for home care assistants was developed, including communication with older people, assistance with personal hygiene, nutrition, food procurement and taking medication (EU Delegation to the Republic of Serbia, 2017). The training enables people to work both in Serbia and abroad as qualified day-care assistants and also to carry out independent tasks in the field of nursing older and ill people living at home. In 2012 the Geronto services were provided in 85% of local governments.

Barriers to change and uptake in practice

Despite the development over the past two decades, the Geronto services are still insufficiently available. The number of beneficiaries covered only 1.2% of the population over 65 years of age, mostly females from urban areas (Center for Liberal-Democratic Studies and the Social Inclusion and Poverty Reduction Unit, 2013). The service was provided on a smaller scale or on a discontinuous basis in 122 out of 145 local governments, among which prevailed small and underdeveloped municipalities, while 15 local governments did not allocate any funds in their 2015 budgets for home care assistance (Matković & Stranjaković 2016).

To improve quality and coherence of long-term care, some countries introduced new roles for professionals specialized in the care of older adults or new (multidisciplinary) teams. In Norway, the role of advanced geriatric nurses, that is nurse practitioners specialized in the care of older adults, has been implemented (Henni et al., 2018). In the Netherlands, a new type of baccalaureate-educated registered nurses, specialized in gerontology and geriatrics, work in long-term care services (Huizenga, Finnema & Roodbol, 2016). To deliver coherent care at district level, the Visible Link programme (2009–2012) promoted the employment of district nurses (DeKlaver et al., 2013; Grijpsta et al., 2013) (Box 7.3). The new role of these district nurses was formalized in 2014 (Batenburg & Kroezen, forthcoming). In addition, there was a shift towards self-managing home care teams (Batenburg & Kroezen, forthcoming). Since 2016, a number of Dutch municipalities have introduced social district teams, aimed at connecting supply and demand of care in neighbourhoods, focusing on the residents' own capabilities (Batenburg & Kroezen, forthcoming). In Belgium, home-based occupational therapy was implemented to adapt the homes of patients to their conditions and

to improve working conditions of home care professionals (Sermeus, forthcoming). In addition, nurses or social care workers received a case management role to allow older people to stay in their own home for as long as possible (Sermeus, forthcoming).

Box 7.3 The district nurse (the Netherlands)

With the aim to provide coherent care at district level, the role of district nurses in Dutch home care had a revival in 2009 (Grijpstra et al., 2013). District nurses were employed in Dutch home care in the 1960s, but their role disappeared later, when policy and economic development led to a reassignment of tasks to other home care workers (Cramm & Nieboer, 2017; den Boer, Nieboer & Cramm, 2017). The so-called new district nurse role is broader than the traditional role and is aimed at the integration of health care, housing, employment and integration (Grijpstra et al., 2013). The district nurse has achieved the lead role in care provision for frail people that live in the community (den Boer, Nieboer & Cramm, 2017).

Contextual drivers

The ageing of the population and the policy trend to enable vulnerable (older) people to stay in their own home for as long as possible, brought the Dutch government to organize support within people's informal networks (den Boer, Nieboer & Cramm, 2017; Grijpstra et al., 2013). Within the political climate in favour of community-based care, the district nurse is seen as a spearhead (Grijpstra et al., 2013). Between 2009 and 2012, the implementation of the new district nurse role took place at national level with the Visible Link initiative. This initiative was aimed at employing 250 extra district nurses (Grijpstra et al., 2013). In 2015, an ambassador programme for district nurses was launched, aimed at increasing the number of new district nurses that are capable of representing and lobbying for their profession at local, regional and national level (V & VN, 2018). Since 2015, district nurses are responsible for people's care needs assessments, which were formerly conducted by the Care Needs Assessment Centre, further strengthening their role (den Boer, Nieboer & Cramm, 2017).

Barriers to change and uptake in practice

The biggest barrier to change and uptake in practice is the shortage of district nurses. Attracting nurses to home care is a common problem in many countries (Drennan et al., 2018). Staff scarcity in Dutch home

Box 7.3 (cont.)

care leads to high work pressure, which might have a negative influence on quality of care and quality of work (Stuurgroep Kwaliteitskader Wijkverpleging, 2018). In recent years, the image of working in home care has suffered, as it has been associated with high work pressure, high administrative burden and a weak role of nurses. This image makes it difficult to attract sufficient district nurses (Zorginstituut Nederland, 2018).

Implementation of reforms

Across Europe older or disabled adults want to stay in their own home for as long as possible and the political climate is favourable to long-term care at home; this has brought several countries to implement skill-mix innovations in home care (De Klaver et al., 2013). There are differences in implementation between different roles, as some roles are more frequently implemented than others. In addition, the implementation of roles may differ across different regions within the same country. The introduction of new professional roles is usually supported by national governments. Incentives and facilitators to implement the skill-mix innovation may be (temporary) funding and legal changes. On the other hand, few large-scale reforms exist. Also, as most skill-mix innovations were implemented only recently, there is little evidence for the success of these innovations, though the formalization of the district nurse role in the Netherlands has shown positive results.

*Palliative care***Skill-mix changes and reforms**

Palliative home care is often delivered by the regular primary health care providers, such as family physicians and community nurses. Palliative care specialists are increasingly available in case of complex needs, yet some countries are still reporting a shortage of specialists in the field to ensure all people in need of palliative care receive it when needed. Overall, most skill-mix innovations identified have involved nurses more than health care professionals from other backgrounds. Task shifting has been introduced as a way to enhance teamwork and access to palliative care. The most frequent task shift identified was between doctors and nurses (Knaul et al., 2018). Often, new tasks were added to the job

descriptions of professionals. Examples were coordination of services, case management and liaison functions between the patient, family and health care professionals (Sekse, Hunskar & Ellingsen, 2018; Thomas et al. 2014; van der Plas et al. 2016). Box 7.4 presents an example of the role of case managers in palliative care in the Netherlands, who are nurses with a specialization in palliative care. Other examples of nurses working in expanded roles in palliative care are nurses from specialized palliative home care teams in Belgium, whose task has been to advise and support other health care providers (for example, family physicians and community nurses) in caring for palliative patients. While performing specialist palliative care tasks in close collaboration with family physicians these nurses enhance the quality of care delivery and at the same time have a bed-side teaching role (Gomes et al., 2013; Seow et al., 2014). Workplace learning occurs through close collaboration with other professionals and as such can help professionals evolve and enhance quality of care delivery (Mertens et al., 2018; Pype et al., 2014, 2015).

Other examples of skill-mix innovations identified in palliative care were trainings for lay caregivers to get involved in the palliative care team by nurses, psychologists and social workers (Farquhar et al., 2016). Receiving training and support from the health care team has been shown to help family members and other informal caregivers to better manage the stress and burden in such complex situations.

Box 7.4 The case of case managers in primary palliative care in the Netherlands

Over the past decade, case managers have been introduced into palliative care in the Netherlands. These are nurses with expertise in palliative care who offer support to patients and their informal caregivers, collaborate with multiple health care providers, and provide continuity between professionals and organizations. A nationwide study investigated the implementation and outcomes of case management showed that compared with usual care, the GP is more likely to know the preferred place of death, the place of death is more likely to be at home, and there are fewer hospitalizations in the last 30 days of life (van der Plas et al., 2015a).

Contextual drivers

This model of case management relies on the principle that basic palliative care is provided by generalists and that specialist care is reserved for complex situations. Most patients are referred early to the

Box 7.4 (cont.)

palliative care trajectory and 62% of referrals are done by hospital staff. The majority (69%) of patients received a combination of curative or life-prolonging treatment and palliative care (van der Plas et al., 2013).

The organizational affiliation of the case managers in the Netherlands varies; case managers can be employed by a home care organization, by a hospice or by a collaborative venture between institutions (for example, a home care organization working together with a hospital). The organizational characteristics have been shown to add more to variability in the number and content of contacts than patient characteristics (van der Plas et al., 2015b).

Barriers to change and uptake in practice

Most patients referred are cancer patients, so broadening the scope to reach other patient groups is important (van der Plas et al., 2015c). The type and number of support actions offered is prompted by characteristics of the organization in which they work and not exclusively by the patients' needs, which could be considered as contradictory to patient-centred care (van der Plas et al., 2015b). Acceptance of and cooperation with providers is pivotal to the success of the intervention. In this context, a survey of general practitioners and community nurses showed that case managers should put more emphasis on building relationships with these providers (van der Plas et al., 2016).

The most frequent innovation however was the introduction of team collaboration through introducing specialized palliative home care teams into the primary care field, along with the regular health care providers. This was the case in 39 out of 46 European countries responding to a European Association for Palliative Care survey (Centeno Cea, 2013), for instance in Germany (Box 7.5). These palliative home care teams consist of specialized nurses, physicians specialized in palliative care, psychologists and administrative support. The palliative-care nurses perform home visits, whereas the other team members mostly have a supportive and supervisory role. In specific patient situations with complex problems, a patient–health care professional contact can be made with the physician or the psychologist. These teams often have a role to support and advise the regular health care providers, although in other countries they actually deliver care in collaboration with the existing health care providers. Another example of introducing collaboration

Box 7.5 Specialized ambulatory palliative care in Germany (SAPV)

Introduced in 2007, the SAPV aimed to improve palliative care in Germany and to give everyone the opportunity to stay at home for as long as possible in the last phase of life. Specifically, qualified teams are composed of specialized nurses, physicians specialized in palliative care, and psychosocial professions and work closely with the volunteer hospice aid. SAPV-Teams are targeting people with a time-limiting, non-curable and progressive diagnosis and complex symptoms, when the intensity or complexity of the conditions necessitates the use of a specialized palliative care team instead of, or in addition to, a general palliative care (AAPV) provided by GPs and other non-specialized providers. The services and skills offered by the teams include a broad range of interventions, from case management, coordination of care, comprehensive pain and symptoms management, psychosocial support, and is available with comprehensive 24/7 services (Kassenärztliche Bundesvereinigung (KBV), 2018). Although there is a clear structural, regulatory and financial division between institutional and ambulatory palliative care, services are provided at home and in home-like settings, such as nursing homes and hospices (Busse, Blümel & Spranger, 2017).

Contextual drivers

Before the introduction of SAPV, palliative care in the home, especially pain-management, was hardly realizable and left patients and informal caregivers more or less alone. Their demand for better support, together with a strong palliative movement that evolved in the past decades were some of the drivers (Enquete-Kommission, 2002; Jaspers & Schindler, 2005) of the introduction of SAPV.

Barriers to change and uptake in practice

SAPV teams are not yet implemented in every region of the country. Contrary to the European Association of Palliative Care's recommendation of 10 teams per million population (Radbruch et al., 2011a, 2011b), implementation rates in Germany range from 0.57 to 6.6 SAPV-Teams per million population (Melching, 2015). In order to counter those regional variations in implementation, quality and practice of SAPV, a national framework agreement has been concluded in 2019 (Deutscher Hospiz- und PalliativVerband e. V. (DHPV), 2018).

Other barriers for uptake of early integration of palliative care in practice is limited access due to tight criteria, for example a life expectancy <6 months (Kassenärztliche Bundesvereinigung (KBV), 2018), bureaucratic issues and workforce shortages (Richter-Kuhlmann, 2017).

was through initiating a network of volunteers (Woitha et al., 2015). These volunteers receive a basic training and their main task is to support the family caregivers.

Finally changing teamwork in existing multidisciplinary teams occurred through adding a palliative care leader, general practitioner and nurse, to a primary health care team (Llobera et al., 2017).

Implementation of reforms

Most innovations have been implemented at local level (in case of research projects or individual programmes, for instance case-manager projects) or at a national level (Arias et al., 2019). Yet, many countries are still reporting a gap in the supply of palliative care to provide timely care for those in need.

Some innovations have been spontaneous practice-based innovations driven by a strong sense of purpose for better patient care, for example, nurses taking up a coordinating role when observing a need. The recognition to improve the quality of patient care has been the main driver in these cases, in addition to the felt need to improve job satisfaction. Other innovations, such as the installation of specialized palliative home care teams or a network of volunteers, were supported by local or national governments. In the case of palliative home care teams, funding and official requirements towards professional qualifications were sometimes initiated and regulated by the government, which can be a policy lever to step up supply and standardize skills requirements.

The WHO recently initiated a pan-European programme that aims to strengthen palliative care competencies of and collaboration between involved health care professionals involved in palliative care (Box 7.6).

7.4 Conclusions

Long-term and palliative care services are expected to see a steep demand in the future. The current and expected future workforce shortages in both areas are likely to generate a need to attract more health professionals with a good mix of skills and educational levels.

For long-term care, a trend observed in many countries across Europe is the strengthening of informal caregivers and various skill-mix changes. Some countries have lowered the skill-sets of their health professionals towards a higher mix of lower qualified professions, such

Box 7.6 WHO collaboration for strengthening of palliative care education of all health care professionals (2016–2020)

The WHO is strongly committed to palliative care as a component of integrated treatment as it improves the quality of life of patients and their families who are facing problems associated with life-threatening illness, whether physical, psychosocial or spiritual (World Health Organization, 2014).

According to a WHO fact sheet (World Health Organization, 2018b), the lack of awareness among policy-makers, health professionals and the public about what palliative care is and the benefits it can offer patients and health systems, beliefs about death and dying, misconceptions about palliative care of being only for the last weeks of life, or misconceptions that improving access to opioid analgesia will lead to increased substance abuse, directly impact the access to palliative care services (WHO Collaboration Centre Paracelsus Medical University, 2018).

To remove this barrier and to ensure that palliative care needs are met together with training of volunteers and education of the public, education and training of health care professionals is of major importance. Therefore, the WHO European Region in collaboration with the newly proposed EAPC Reference Group on Palliative Care Education and Paracelsus Medical Private University (PMU) in Salzburg – a WHO Collaborating Centre – are working towards innovative solutions to cultivate and support interdisciplinary and intersectional collaboration across different health care sectors. The collaboration started in 2016 and aims to develop a matrix for a pan-European curriculum to assist in the promotion and embedding of palliative care into health care professional curricula at undergraduate and graduate level (WHO Collaboration Centre Paracelsus Medical University, 2018).

The goal is to break down the myths about palliative care and support health care professionals' collaborations across all fields of responsibility, for example, through provision of an online learning environment for strengthening palliative care education of all health care professionals by 2020 (WHO Collaboration Centre Paracelsus Medical University, 2018).

as health care assistants, or lay workers. Other countries have enhanced the skill-mix to improve the quality of care by introducing specialized professionals, such as the district nurse in the Netherlands (Box 7.3), or case management and multidisciplinary teamwork. The outcomes

seem promising, at least for some outcome parameters, but are based on limited evidence.

Across Europe, in long-term care, several countries have changed the skill-mix towards lower-qualified professionals, with a focus on training informal caregivers. In other countries, job opportunities for unemployed or migrant populations were created, but with limited information on outcomes. On a small scale, tasks are allocated from better-qualified towards less-qualified staff. Until now, there was little evidence on the success of these innovations. However, for most countries in Europe, family members acting as informal caregivers should receive more support, both in their skills, competencies and coping strategies, including from professional teams, if they want to take up the caregiver role.

In terms of improving the quality and accessibility of long-term care at home, one promising large-scale reform is the formalization of the district nurse role in Dutch home care (see Box 7.3).

In long-term care, with the exception of case management interventions, especially for people suffering from dementia and their caregivers, there is in general little scientific evidence on the outcomes. In dementia care, case managers have shown promise in selected outcome parameters, for example, case manager roles may reduce feelings of isolation and embarrassment of the condition. It was also shown to improve coping with memory problems, to improve patient access to services and professionals' compliance with guideline recommendations. Yet, in long-term care for patients with conditions other than dementia, scientific research that examines the effects of different skill-mix models on specific outcome measures, health professionals and caregivers' roles is needed.

The same applies for palliative care, where evidence on effects of skill-mix changes is scarce. With the increased public attention on patient needs at the end of life, policy-makers across Europe are increasingly seeking strategies to improve the quality of care and ensure palliative services for all in need. Several countries have introduced palliative care skill-mix changes to teams, but in most cases they remain small in numbers and without ensuring everyone has timely access.

The most frequent skill-mix intervention in European countries is the introduction of palliative home care teams that bring specialized knowledge and skills to the patient's home and ease pain and suffering, often at the end of life. The evidence suggests that there are several

benefits to patients and their caregivers and family from skill-mix changes that offer more specialized palliative care. Moreover, the professions involved in providing palliative care may also benefit, and there is some, but limited, evidence on reduced hospitalizations. To optimize the collaboration with each other and with the palliative home care teams, education and training of health care professionals should entail interprofessional collaborative competencies from the undergraduate level throughout the lifelong learning trajectory.

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