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The Family as Recipient and Provider of Home Care: A Primary Care Perspective

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Abstract

Advances in modern medicine, effective medication and high-technology interventions contribute to the growth of chronic comorbidities among older people, and many children with chronic diseases that reach adulthood require long-term care at home, provided by formal and informal caregivers and coordinated by primary healthcare professionals. Home caring, performed under different conditions from those of hospital care, requires the involvement of the family that is recipient and provider of home care. This chapter discusses the contribution of family caregivers to personalized home care of dependent children and elderly recipients, coordinated by primary health professionals. Children and youth with special healthcare needs and children abused and neglected require special involvement of family caregivers. The use of digital healthcare for recipients with medical complexity is a modern way to connect home care patients to specialized care, reducing the costs of the hospital care system. However, the burden in home care should be recognized by the general practitioner. Specific interventions are addressed to the unsupportive families and real hidden patients to help maintain their health and functionality. Future family doctors' interprofessional communication skills and resourcefulness should meet the societal changes, and the burden of home care in the modern family is approached from the perspective of academic medicine.

Keywords: family caregiver, home care, recipient, provider, primary healthcare professionals

1. Introduction

The demand for home-based care rises with an ageing population, with elderly people suffering from multiple comorbidities that require long-term management at home [1]. Moreover, due to the advances in modern medicine, efficient medication and high-technology interventions, many children with chronic illnesses reach adulthood, requiring long-term care at home coordinated by family doctors and community nurses. The number of people aged 60 and older is expected to grow from 962 million in 2017 to 21 billion in 2050 in Europe [2].

The proportion of people aged 65 years and older is expected to grow to an average of 28% in the Organisation for Economic Co-operation and Development (OECD) countries in 2050, while in some countries (e.g. Japan, Spain, Portugal, Greece and Korea), a share of 40% is forecasted. China's proportion of older people will triple between 2015 and 2050, and also in the USA, Mexico and Israel, these

growing trends will be influenced by higher rates of fertility and migration. Higher age is associated with higher morbidity, which in turn affects care dependency [3, 4]. Prognosis regarding the number of people in need of care shows an increase of 115% in the European Union between 2007 and 2060, and the number of people in need of care in the USA is expected to double from 13 million in 2000 to 27 million in 2050 [5]. Experts anticipate that older adults will comprise 13% of the total population—one in eight people will be 65 or older by 2030 [6].

The healthcare system is changeable and unsteady; the period of hospital admission is limited by the high costs, and the trend is to continue the long-term management by the formal and informal home care providers. The chronically ill patients feel rushed from the hospital and worried because they do not have adequate care in the community, especially in rural areas. Patients are discharged with drainage tubes, urinary wells, nasogastric tubes, open wounds and insufficient pain control, and family members are unprepared for the needed care in these complex contexts. In addition, they face limited money and consequences related to their work and child-care. To meet the current challenges in the home care of the frail elderly and children with disabilities, it is a requirement to strengthen the role of informal caregivers [7].

1.1 Family as a recipient of home care

The family as a recipient of home care has a lot of worries with possible unrealistic expectations. Sometimes, patient's family members are upset, unresponsive or hostile to the home care team. The family is the hidden patient, sometimes acting as a dysfunctional, unsupportive family, with a high perception of the burden of care. Primary care professionals should identify these families that require evaluation and specific interventions to become effective while maintaining their full health status and functionality. Family physicians and community nurses are called upon to build trust, making it clear to the family that they are available to them, explaining the plans of care after discharge, resolving any miscommunication and diminishing concerns about caring for their loved ones at home. These are the persons who they trust, with whom they had the continuity and the relationship. Primary care professionals have an ongoing history with patients, building an agreed relationship over time even in difficult times of an advanced chronic disease or end-of-life care. They need to verify the recipients and his/her family feelings, let them know that they will be listened to and their concerns understood and try to identify an informal home caregiver to work with.

1.2 Family as provider of informal home care

Family caregivers as informal home care providers have an essential role in ensuring the care of the frail recipients at home [7]. Informal caregivers are defined as individuals who are actively and directly involved in the recipient's home care and who repeatedly support and assist with care, without being paid. They provide ongoing assistance with activities of daily living (e.g. toileting, feeding, bathing, walking, clothing) or instrumental activities of daily living (e.g. meal preparation, housecleaning and managing finances), for individuals with a chronic illness or disability [8, 9].

The primary caregivers, most often the family members, are usually people who are not trained in the process of care and are unprepared for facing difficult situations, making the negative impact stronger in the family evolution. The majority of the general population wishes to stay at home in old age and would prefer to receive informal care from their adult children or formal care from home assistance services [10]. However, the decision of family members to take care of a dependent person, and thus fulfilling his/her wish to age in a domestic environment, is influenced by the

degree of family relationship and the willingness of family members to be involved in home care [11]. Although, traditionally, in Romania, the primary caregiver was a family member, in recent decades due to migration of active people working abroad, their elderly parents are cared for by friends or neighbours at home. In addition, there is great need to develop home assistance services and community care units for long-term care recipients with multi-morbid chronic diseases. The caregiving experience varies by the diversity of caregiving activities, time commitments and distance. The proximal caregiver provides assistance with personal care, while long-distance caregivers are involved in offering emotional and social support and financial assistance.

The family as provider of informal home care is recognized and valued by the primary healthcare professionals that acknowledge working with family caregivers is the best way to ensure quality outcomes for their recipients. Most physicians (88%) acknowledge seeing better outcomes and higher formal caregiver satisfaction (73%) when they collaborate with families [12]. However, doctors and nurses found that sometimes establishing communication with family caregivers can be challenging. About half of the formal providers (54%) say a recipient having multiple caregivers was a barrier, 44% are not aware who the caregiver is, 44% say there is fluctuation in caregiver involvement, and 39% felt interacting with caregivers was too time-consuming. Among those who felt communication was difficult (20%), most said the inability to reach out to the caregiver was the primary issue [12]. Formal home care providers and informal family caregivers focused on drug administration and meal service, organizing transportation for follow-up visits, discussing the recipient's emotional issues, managing the family caregiver's burden and encouraging more collaboration.

Delegated interventions provided by family caregivers and coordinated by primary care health professionals contribute to a more proactive, personalized and integrated care for recipients with long-term comorbidities [13].

2. International validated tools for the family assessment in primary care

Home care is the health or social service provided by formal and informal caregivers for the recipient who cannot go to the general practitioner (GP) surgery or to the other levels of health services. Eurostat data from 2016 show that 20% of households needed to use professional home care services. The rate of use of home care services is very different: 88% in Luxembourg, 58% in the Czech Republic and only 6% in Romania [14]. Evaluation of the family as recipient and provider of home care comprises four domains: demographic facts, psycho-emotional domain, environment aspects and family burden as caregiver.

2.1 Demographic facts

Information about the family's structure, number of members, education, employment status, living place, family network and members with chronic illness or with disabilities are obtained using a self-administrated questionnaire or an interview. Genogram is a brief tool that should be used in the home care consultation, a system helping to identify the vulnerable recipients in the family. This graphic representation includes all family members, alive and deceased, unrelated persons living in the same place, their relationships, hereditary or recurrent illness, drug addiction and issues related to the elderly or child neglect and abuse [15].

The Resident Assessment for Home Care (RAI-HC) was developed following a high demand for a standardized evaluation of the patient's needs through a comprehensive home care system. This instrument addresses frail elderly and patients with chronic

diseases and disabilities. Although a 60-minute duration of the evaluation may be a disadvantage, this tool offers a comprehensive analysis of the recipient, informing the home care provider about demographic characteristics, nutrition, health behaviours, types of diagnosis, functional and cognitive status and health instability (frailty).

The Resident Assessment for Palliative Care (RAI-PC) is an instrument that evaluates the symptoms most commonly seen in palliative care patients: pain, dyspnoea, fatigue, mental capacity, cognition, overall physical tonus and capabilities for self-care.

The needs of the palliative patient, his/her family and the caregivers are constantly changing, which leads to the need to regularly apply RAI-PC, both to the patient and to his/her caregivers.

The shorter duration of the evaluation by RAI-PC is appropriate for the palliative patient and his family. In addition, an important feature of this tool is its quality to evaluate the effectiveness of many types of interventions, establish a comparison between interventions and provide information for cost-effective management of the patient with palliative care needs.

2.2 Psycho-emotional domain

The old age, female gender, long-term provision of home care and type of illness are predictive factors for the emotional stress of the family caregiver [16]. Early identification of high-risk psycho-emotional pressure enables effective interventions of GPs and community nurses. The Family Relationship Index (FRI) is the family relationship assessment tools, developed by Holahan and Moos in 1983. Through its three scales, it explores family cohesion, expressiveness and conflicts, helping the professional home care team and collaboration [17].

2.3 Assessing the need for family support as home care provider

The support needs of family as caregiver refers to the environment/habitat, financial support, help for nursing techniques, the level of preparedness for the caregiver role and educational needs for the caregiving process.

2.3.1 Family social support need

The Oslo Social Assistance Scale (OSS-3) assesses people close to the patient, how much they are concerned about home care and who the recipient would ask for practical help if needed [18]. Another aspect of the social support refers to the financial well-being of the family. In 2006 Prawitz developed the Financial Distress/Financial Well-Being (IFDFW) tool which evaluates the perception and concerns about family financial status. The low score shows the high level of financial distress, leading to an increasing deterioration of health [19].

2.3.2 Preparedness of family for the caregiver role

The Preparedness for Caregiving Scale (PCS) described by Archbold, Stewart, Greenlick and Harvath, in 1990, is an instrument with eight items that ask family caregivers how much they are well prepared for the challenges of caregiving. The lower score signifies the poor preparedness for the caregiver role [20].

2.3.3 Family caregiver burden

The caregiver burden is a negative experience perceived by the person involved in the long-term home care. The Burden Scale for Family Caregivers (BSFC) is a

useful tool, assessing the subjective burden perceived by the caregiver in home care. In Romania, GP involved in home care identifies the family caregiver's burden only by a holistic evaluation, without using an instrument for the burden of care assessment. The BSFC instrument started to be used in Romanian primary palliative care research. Measuring the burden of home care allows early interventions for family caregivers and secondary prevention.

3. Interventions provided to the family caregivers by the primary healthcare professionals

3.1 Psycho-educational interventions

The psycho-educational interventions provided to the family caregivers are focused on the preparedness of family for the caregiving role, help for emotional reset, encouragement to identify the positive aspects of this experience, promotion of self-care, respite care and advising for new problem-solving strategies. There are different forms of psycho-educational intervention: individual session face-to-face, focus groups and e-learning programme with an online professional teacher. A useful method is the family meeting, having the following advantages: provides training of caregiver for proper nursing techniques, facilitates discussions about the disease' prognosis, updates the home care goals and establishes a concordance between care goals and the recipient's desires. In addition, it is a good moment to share the patient's preferences, to reduce stress, anxiety, depression and emotional changes in end-of-life care [21]. The principles for conducting family meetings are clarifying targets of care, refreshing the knowledge about the disease, anticipating future challenges and offering solutions in accordance with the family needs [22].

3.2 Supportive interventions

Social support is defined as the existence or availability of people on whom individuals or families can rely on difficult times. The support interventions for family caregivers include groups or individual sessions, being conducted by professionals. Group-based support is the most common form wherein the whole family participates, including the patient. In this method experiences are shared, leading to positive changes regarding the personal confidence, acceptance of the family caregiver role and adoption of new coping skills [23]. Applying flexible and individualized forms of support interventions helps reduce the burden of caregivers and increases the knowledge about home care and ability to cope with difficult situations [24].

4. Home care interventions delegated to the family caregivers

4.1 Physical domain

The physical domains of home care such as hygiene of the recipient, proper mobilization of the patient in bed, daily chest massage and oral cavity cleaning are daily medical manoeuvres which are delegated to the family caregiver by the GP. Family caregivers' education about the treatment is mandatory and implies the administration schedule, onset of action, routes of administration and possible side effects. The fulfilment of the treatment plan involves the following interventions: (a) medication administration by different routes (oral, rectal, percutaneous, enteral or using a nasogastric tube) and (b) monitoring of symptom control by

the family caregivers. Warnings regarding late-release medications, which require administration at fixed times, and fast-release medications, which are administered when needed, are important. The family caregiver should record in a diary the problems they are experiencing, the side effects of the drugs and the presence of intestinal transit. Some medical interventions can be assigned to a certain family member as long as he/she is well trained and if a safe device is used (e.g. administration of the medication subcutaneously by a microperfuser) and will be supervised by the GP and community nurse.

4.2 Psycho-emotional domain

The psycho-emotional aspect of the home care is burdensome for both the recipient and the family caregiver, affecting the formal home care team as well. Interventions delegated to the family caregiver imply discussions on pleasant topics, keeping in touch with the patient's friends and creating an enjoyable environment. Keeping honesty about the diagnosis, treatment and evolution is a desideratum of communication. Solving family conflicts, establishing good relations between its members and paying attention to people at risk especially for children will complete the care, keeping family members involved in the home care process. Cultural values and spiritual beliefs should be respected.

4.3 Social domain

The social support includes financial assistance, emotional support, information, companionship and self-esteem support. Inadequate social support and social isolation are associated with increased depression [25], cognitive decline, increased pain intensity and increased mortality [26]. The social needs are addressed by the social assistance specialist, and some can be delegated to the patient's family. The family caregiver will create a socially appropriate environment by avoiding isolation and participating in social or religious events and walks, depending on the degree of patient dependence.

5. Home care for children

5.1 Introduction

Defining health like a human right, the United Nations Convention of the Right on the Child (UNCRC) ratifies the importance of the different aspects of child health in all types of care. In 2018 the global under-five mortality rate declines worldwide, but 5.3 million of children died under 5 years due the complications of prematurity, pneumonia or diarrhoea. The care of health especially on ill children is a permanent task for all health system, providers and caregivers. The World Health Organization (WHO) guide "Improving the quality of pediatric care -Operational guide for facility-based audit and review of pediatric mortality" provides data for the improvement, modifies the social, environmental and nutritional risk factors and supports healthcare workers by learning their medical practice [27].

5.2 Home care for healthy children

5.2.1 Planned home birth

The prevalence of home birth is variable by country, from 0.4% in Australia to 3.3% in New Zealand, with the highest percentage being in the Netherlands (20%) [28].

Even in countries with no tradition in home birth and a low prevalence of planned home birth, mothers show a growing interest for non-medicalization of a natural process. Until recently home birth was widespread, with more than half of the pregnant women giving birth at home in the 1940s. Due to the significant increase in the number of hospital beds and controversies about the safety of home birth and population mobility, the prevalence of planned home birth decreased.

The motivations of the women who desire to give birth at home are related to concern about the high medical interference (induction of labour with oxytocin, peridural anaesthesia and caesarean birth), cultural and religious background, unpleasant previous hospital experiences and the wish to give birth in the family environment [29, 30].

The main concern about out-of-hospital birth comes from the connection between perinatal and neonatal mortalities and the place of childbirth. A meta-analysis based on 14 studies and ~500,000 planned home birth of low-obstetrical risk women demonstrated no statically significant difference regarding perinatal or neonatal mortality between low-risk pregnant women who intend to give birth at home and those who opt for the hospital. All the studies were performed in well-resourced countries, and the midwives were well-integrated in health system.

The study revealed that multiparous low-obstetrical risk women are more eligible for home birthing than nulliparous [31].

The safety of home birth is possible in countries with well-integrated healthcare programmes, including an educational programme for proper knowledge about low-risk pregnancies and specially trained midwives. The Dutch midwifery care is one of the best organized systems. The Dutch midwives provide antenatal care and attend home birth. They are trained for the follow-up of low-risk pregnancies and are able to recognize and manage some complications. If women become non-eligible for home birth, they are referred to secondary/tertiary care centres. Their Obstetric Manual (Verloskundig Vademecum) stipulates the agreement to be part in a complex, collaborative team involved in home birth and the clear stratifications of obstetrical risk. The recommendations of the American College of Obstetricians and Gynecologists stipulate that foetal malpresentation, multiple gestation or prior caesarean delivery are absolute contraindications to planned home birth [32]. The optimal candidates for home birth are women who express the option for home birth after being counselled on risks, benefits and alternatives. It is considered that eligible women for home birth are those who have no pre-existing medical and obstetrical conditions, with singleton full-term cephalic foetus having a weight appropriate for gestational age, with spontaneous labour and prior vaginal birth. It is essential not to overlook that home birth may not be a preference of the pregnant woman and can be caused by lack of proper transportation, local maternity facility or insurance/financial resources.

5.2.2 Home care for full-term newborn

One of the characteristics of primary paediatric care in most of the countries is that home care for a healthy newborn starts after discharge with a follow-up medical visit taking place at the family home. The timing of follow-up visits is recommended to be done according to the duration of hospitalization, the discharge medical data and availability of the family and healthcare provider [33]. It is advisable for the healthcare provider to schedule it in such a way as to allow a generous amount of time. The durations of the visit must be appropriate to the complexity of the content of the follow-up visit.

According to the reproductive-maternal-newborn-and-child-health (RMNCH) indicators, alongside a complete physical examination, it is necessary

to review some aspect of pregnancy, delivery and period from discharge [34]. It is also important to review the screening tests, to promote breastfeeding, to enhance the interest and to raise awareness regarding immunization. Involving the members of the family (father, grandparents) and observing the communications in the family allow the primary paediatric provider to coordinate a health plan, if needed.

For the newborn and mother, the WHO recommends the use of home-based records in order to improve some aspects of care. These include developing childcare knowledge, nurturing, involvement of the male in the child home care practices and communication between health providers and caregivers. There is not enough evidence in favour of a certain type of home-based record, the efficiency depending on the specific culturalism of a country [35].

The general practitioners' activity, especially the one with interest for child's care, is under a permanent challenge due to misinformation from online media. One of the most popular topics promoted in many countries by social media is the anti-vaccine movement linked to immunization of children and adults.

Social media platforms like Facebook and Instagram have become an important source of medical information for patients, caregivers, healthcare providers and policy-makers, and they must assume responsibility towards their users. The statement released in September 2019 by WHO Director-General Dr Tedros Adhanom Ghebreyesus raises awareness on the importance of social media platforms for spreading such information.

The World Health Organization welcomes the commitment by Facebook to ensure that users find facts about vaccines across Instagram, Facebook Search, Groups, Pages and forums where people seek out information and advice.

Facebook will direct millions of its users to WHO's accurate and reliable vaccine information in several languages, to ensure that vital health messages reach people who need them the most [36]

5.2.3 Home care for a healthy preterm baby: neonatal discharge planning

The infants who are born preterm are generally cared for in neonatal intensive care units (NICU), and a discharge planning is necessary for a comprehensive method. Because of the rate of mortality and morbidity, they are considered newborns with high risk after discharge.

Home care for the preterm newborn is coordinated by a complex team of caregivers: physician, paediatric primary care provider/family doctor, nurses, occupational and/or physical therapists, dieticians, pharmacists, parents and social workers. Neonatal discharge planning is developed in four major aspects:

- The complete assessment of the newborn, routine screening and vaccination schedule and, if necessary, planning the follow-up for specific conditions
- Readiness assessment by care providers, including parents and family environment
- Recognition of risk factors and link of the family with community services for support after discharge
- A smooth as possible transition from NICU to primary care and medical home

Respiratory control, maintaining normal temperature (axillar 36.5–37.5°C and rectal temperature 36.6–38°C) in an ambient temperature of 20–22°C, oral feeding skills (breast and/or bottle) and an ascendant parallel growth curve are mandatory for planning the discharge of the preterm infant.

A complete routine screening must be performed before discharge, and ophthalmological, hearing and prematurity anaemia screening must be included in the follow-up programme. The schedule of vaccine is planned according to the chronological age of preterm infant and follows the same schedule of a full-term newborn. Before discharge it is mandatory to observe the preterm infants for a minimum period of 90–120 minutes while sitting in a car safety seat because of frequent oxygen desaturation and episodes of apnoea, hypotonia or bradycardia. Families/caregivers should be trained by hospital staff regarding the proper position in the car safety seat [37, 38].

The parents/primary care providers of preterm infants planned to be discharged from NICU must prove competency in daily care regarding breastfeeding/bottle feeding, care for the infant's skin and genitalia and the way the baby is bathed and clothed. It is necessary for the parents/caregivers to demonstrate some basic medical knowledge on the possible signs of illness, like changes in pattern of feeding or sleep, significance of dry diapers or modifications of the stool aspect. The caregivers must be able to monitor the temperature of preterm baby, evaluate the respiratory pattern and skin colour and assess the muscular tonus. It is important to educate the parents/caregivers about the safe sleep position for preterm infants as they must sleep alone on a plan surface and in a supine position [39]. The readiness of parents to care for newborns discharged from NICU should be assessed in order to improve the discharge preparation process. A parental and nurse survey demonstrated that iterative improvements of the discharge preparation process lead to an increase in family self-assessment of discharge readiness and in nurse assessment of the family's emotional discharge readiness [40].

5.3 Home care for children with special healthcare needs

5.3.1 Children and youth with special healthcare needs (CYSHCN)

The definition of this category of children has become more comprehensive during time, and now it is accepted that CYSHCN are those “who have or are at increased risk of developing a chronic physical, developmental, behavioral, or emotional condition and require health and related services of a type or amount beyond that usually required by children” [41]. More than a quarter of families have at least one child with special healthcare needs. Data from the 2016–2017 National Survey of Children's Health (NSCH) indicate that 18.8% of children <18 years of age in the USA have special healthcare needs, with 13.2% of children being medically complex.

In Western Europe non-communicable diseases (NCDs) for children under 15 represent almost 75% of the total diseases related with disability-adjusted life years (DALYs). In the first month of life, complications due to prematurity are the leading cause of death and DALYs, the second cause being congenital anomalies, which then holds the leading place until the age of 4 years. Some of these causes of death or DALYs for children are largely preventable as they are especially due to road injury, drug and alcohol use, smoking and poverty [42].

The framework of care for CYSHCN comprises the Standards for Systems of Care for Children and Youth with Special Health Care Needs, version 2.0 [43]. It is necessary to coordinate all the parts of care, comprising family professional partnership, medical home, insurance and financing and early and continuous assessment of needs. All these elements have to be culturally and linguistically

appropriate for an optimal understanding and acceptance. The primary care provider and/or paediatric subspecialist evolving in an integrated team of care has to encourage the children and their families in self-management of issue of health and seeking advice for a good quality of life, healthy behaviors throughout all stages of life. Cooperation with the other caregivers involved in the care process must ensure an efficient and prompt sharing of information inside the team.

Care mapping for family and professional caregivers is available in some medical units, and designing a care map provides a valuable work tool.

Primary and preventive care is similar for CYSCHN and children without special needs. The routine healthcare maintenance comprises the vaccinations, routine screening and surveillance, assessment of visual and hearing impairment, behaviour and mental health problems, maltreatment, neglect and dental care.

An anticipated guidance for CYSCHN and their family should include information about the possible complication of disease, the short and long prognostic of illness and the manner in which the disease may affect the child's development, behaviour and potential to accomplish daily activities and family life.

The professional caregivers can enlighten children and the family about the possibility of illness exacerbation or relapse, changes in treatment or future procedures. The family of a child with special health needs, especially his siblings, is in risk to develop psychosocial functional stress and hence requires surveillance [44].

The partnership between caregivers, patient and his family centred by medical, social, developmental, behavioural, educational and financial needs of CYSHCN defines the concept of care coordination [45]. The plan of care must consider the patient and family health goals, a list of barriers, an inventory of medical supplies, home nursing, therapy plans, contact information for all caregivers, feeding plans and educational support. Home care services are more frequently provided to CYSHCN by the members of family and/or different types of caregivers.

5.3.1.1 Chronic lung and pulmonary vascular diseases

Home care for children with chronic lung disease, pulmonary hypertension with or without congenital cardiovascular malformation, metabolic disease, children's interstitial lung disease (ChILD) or haematological disorders has multiple benefits for the child and his family. Among them are the improvement of psychological aspects of the child's development, avoiding the family caregivers' burnout syndrome and a lower cost than hospitalization. The need of children with chronic hypoxaemia for home oxygen therapy (HOT) may be assessed by pulse oximetry. This is an important conclusion of the Clinical Practice Guidelines of the American Thoracic Society who strongly recommends HOT for children with cystic fibrosis and severe hypoxaemia, bronchopulmonary dysplasia with chronic hypoxaemia and pulmonary hypertension without congenital heart disease. HOT is conditionally recommended for children who cannot support positive airway pressure therapy for sleep breathing disorders with severe nocturnal hypoxaemia. For ChILD complicated with severe hypoxaemia, HOT is strongly recommended, while for ChILD with mild chronic hypoxaemia, dyspnoea or sleep desaturation, HOT is conditionally recommended. The chronic untreated hypoxaemia influences the growth parameters, the neurodevelopment milestones achievement and the architecture of sleep. Some studies even relate hypoxaemia with brief resolved unexplained events (BRUEs) [46].

5.3.1.2 Home care for children with cerebral palsy

Cerebral palsy is defined as a "group of permanent disorders of the development of movement and posture that cause activity limitations that are attributed to

nonprogressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior and by epilepsy and secondary musculoskeletal problems” [47].

In the neonatal period, successive evaluations have to be performed; some abnormality in muscle tonus, coordination, reflex and posture must be assessed and referred to the neurologist if needed. Primary care providers (physicians, physician assistants and nurse practitioners) are expected to develop an interventional plan according with the family structure, resources and possible target.

5.3.1.3 Home care for children with congenital heart disease (CHD)

Congenital heart disease is the most common congenital anomaly. Due to surgery and advanced palliative therapies, the survival of children with special needs has increased. The American Academy of Pediatrics (AAP) and the American College of Cardiology (ACCA) reviewed the current literature and provided a policy statement whose purpose was to highlight the role of primary care providers in the management of patients with CHD and their families during all phases of life.

The role of primary care providers was emphasized by the chronological approach of life stages of children with CHD. Parental counselling, support and coordination of care cover all stages of life, while prenatal diagnosis, predictive of neonatal need, early diagnosis of CHD, nutrition, growth and development, immunizations and academic and future career support are specific for specific periods of life.

Some particular requirements are important for the care of child with CHD: special immunizations (seasonal respiratory syncytial virus, influenza, vaccination for close contacts), nutrition and feeding issues (optimal growth velocity), obesity, practicing a sport and transition to adult care (especially for girls: appropriate contraception, teenage pregnancy) [48].

5.3.2 Child abuse and neglect

Child abuse and neglect is a complex and hypersensitive issue. Child maltreatment is a public health problem with lifetime health impact for children and their families [49]. Child maltreatment is defined by the World Health Organization as “all forms of physical and/or emotional ill-treatment, sexual abuse, neglect or negligent treatment or commercial or other exploitation, resulting in actual or potential harm to the child’s health, survival, development or dignity in the context of a relationship of responsibility, trust or power” [50]. Children who have experienced maltreatment are at greater risk to evidence antisocial conduct, aggressive behaviour and substance abuse as a coping mechanism [51]. Chronic stress in early childhood alters the function and structure of the developing brain [52], influences the immune system function [53] and increases inflammatory markers [54], associated with physical and mental health disorders [55, 56]. Abuse and neglect of a child may take many forms. Physical abuse is an intentional injury caused by a parent or a caregiver upon a child. Physical child abuse can lead to serious physical injury, the most common form of abuse being bruising, but it can lead to severe fractures or even death [57, 58].

Sexual abuse is an exploitation of a child in any sexual manner. It is not restrained to physical contact such vaginal, oral or anal sex between an adult and a child and may include noncontact abuse, such as exhibitionism, fondling a child’s genitals, masturbation in front of the child or forcing him to masturbate, sexual harassment by obscene phone calls or text messages and child pornography and prostitution [59].

Child marriage is considered a disguised form of sexual abuse, and it also represents a violation of children's rights. The boys are also concerned, but girls remain disproportionately affected. Poverty, lack of education, regional customs, tradition and religions can be a pressure that leads to child marriage. Child marriage is most common in developing countries, but it happens even in developed countries as many countries' laws allow children under 18 to marry upon parental consent or public authority. This practice denies children of their right for childhood, education or having their own opinion about sexuality and reproduction. Child marriage is linked to early pregnancy, health risks like sexually transmitted infections, obstetric fistula and maternal mortality.

Emotional abuse is a behaviour model that affects a child's emotional development and his health outcome. It is more challenging than physical or sexual abuse, being often difficult to diagnose. Emotional abuse can lead to anxiety, depression, low self-esteem, post-traumatic stress disorder and suicidal tendency.

Medical child abuse or factitious disorder imposed on another (previously called Munchausen syndrome by proxy) is an unnecessary and a potentially harmful treatment received by a child due to a caregiver seeking medical help for exaggerated or made-up symptoms of the child in his or her care [60]. It should be suspected if the child has frequent, unexplained health issues and multiple hospital admissions. The most common form when a mother induces an illness to her child consists in symptoms that usually occur only in her presence and may not be objectivized during the medical evaluation [61]. Neglect is very difficult to conceptualize, being an omission behaviour, and consists in failure of a parent or a caregiver to address the basic needs of a child. It can include physical necessities like food, hygiene, clothing, shelter or protection, educational (schooling and education) and medical neglect defined as a failure to provide necessary medical, dental or mental healthcare for the child [62].

Refusing vaccination can also be considered "medical neglect".

Child maltreatment provides a significant challenge for medical providers. Practitioners have an important role in prevention and recognition of neglect and abuse and assessment and treatment of children at risk. Once the condition is suspected, they are obligated to report it. Programmes of prevention and intervention aim for early recognition and intervention to protect children's wellbeing.

The primary approach is addressed to the general population by an anticipatory guidance for parents and care providers and by implementing media content and school programmes to educate the population about signs and behaviour of child abuse and neglect.

The secondary approach is addressed to families if risk factors such as poverty, low education, substance abuse, mental health issues, family conflict or violence, social isolation, neighbourhood disadvantage and violence are present. The purpose of intervention is to encourage positive interaction between parent and children and to break down the coercive cycle [63].

Families with abused or neglected children may benefit from a tertiary approach. To assess these cases, the multidisciplinary team should consist of therapist, social workers, police, general practitioner, paediatrician and teachers. An individual plan best suited to the family needs (e.g. individual therapeutic interventions, home visiting, family behaviour therapy, social integration) has to be established. If the intervention fails, foster care system may be considered. In this case certain challenges need to be acknowledged: managing challenging behaviour, interacting with biological families and even guiding children into adoption.

5.4 Worldwide tendencies: community health worker (CHW), misinformation, and telemedicine in home-based care for children

The community health worker, named as such in the USA and defined as a front-line public health worker who is a trusted member of the community, is present under different names in several European countries [64]. This trusting relationship enables the worker to serve as an intermediary between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery [65]. Preventive maternal and child health (MCH) interventions delivered by CHWs through home visiting have improved important maternal and child outcomes. Efforts are targeted towards early prenatal care, breastfeeding, reduction of maternal morbidity and perinatal mortality and appropriate childhood immunizations. Home visiting interventions lead to a decreased incidence of preterm birth and low birthweight [66]. By having a common language, a similar socioeconomic status and understanding life experiences of their clients, CHWs are accepted by vulnerable and disenfranchised groups. Being integral contributors in collaborative health-based and community-based teams, CHWs improve comprehensive care and contribute to health improvements and cost savings [66].

Misinformation has reached an unprecedented level in the digital age. Forums, blogs and other alternative news sources facilitate fake news or inaccurate information penetration. Health information at every level, from ordinary people to researchers and policy-makers, is troubled by misinformation. It can contain false narratives and lead to poor decision-making and dangerous behaviours [67].

The Internet is a rapidly evolving territory. Intentionally or unintentionally misleading or provocative information may have serious consequences [68].

A research performed on 210 subjects showed, as expected, that people use search engines to learn about serious or highly stigmatic conditions, but surprisingly, an important amount of sensitive health information is sought and shared via social media [69]. The term telemedicine meaning “healing at a distance” was introduced in 1970 [70].

An international Group Consultation on WHO’s Telemedicine Policy adopted the following definition for health telematics: “Health telematics is a composite term for health-related activities, services and systems, carried out over a distance by means of information and communication technologies, for the purpose of global health promotion, disease control and healthcare, as well as education, management and research for health” [71].

Telemedicine can be synchronous or asynchronous. Synchronous or “real-time” care consists in a bidirectional audio-visual videoconferencing between a patient and a more or less remote healthcare provider. Asynchronous or “store-and-forward” care comprises the transmission of medical information to a distant provider.

Telemedicine in children may be useful in improving paediatric concussion care in remote areas and communities [70]. Although international guidelines recommend urgent medical assessment after a concussion [72], a study on 126,654 children and youth showed that, at best, only one third of youth sought medical follow-up and obtained clearance to return to sport activities [73].

In many countries, including Romania, patients living in remote rural areas face numerous geographic, socioeconomic and cultural barriers in accessing primary and specialized healthcare services. Considering the fact that especially in these areas medical assessment and clearance for youth with concussion falls upon primary care providers, telemedicine would improve results and ease the pressure of malpractice.

Telemedicine and telehealth devices can improve and facilitate care in children with medical complexity. A single-centre nonblinded randomized clinical trial based on tracheostomy status demonstrated that the group utilizing a telehealth device obtained better results. Thus, at a device connectivity of 96% of the time and image and sound quality acceptable in 98% of visits, hospitalization rate was lower in the telehealth group [74].

Improvement of care in children with complex medical conditions has increased survival, contributing to a continuously rising percentage of paediatric population with chronic healthcare needs. The highest prevalence of children with special healthcare needs (19.8%) is estimated to be in the USA [75].

Introduced mainly to reduce the need for urgent care leading to recurrent emergency department visits and hospital admissions, synchronous digital health technologies are expected to improve parental caregiver outcomes such as quality of life, psychological health, satisfaction with care and social support. As expected, the majority of the papers on this topic originate from the USA and Australia. The explanations lie in the higher economic level but also in the necessity to cover by telemedicine remote areas with few inhabitants [76]. Feasibility-related outcomes were conducted on haematology/oncology/palliative care populations, autism spectrum disorder, asthma or mental health issues and included assessing acute clinical issues, providing psychosocial support, facilitating case conferences, providing routine care and follow-up, delivering therapy and monitoring progress and adherence acceptability [76].

The technical problems encountered were, as expected, both human related and technology related.

The programmes were aiming to provide patient care or replace in-person assessments. Telemedicine was delivered by a multidisciplinary team or nurses with various levels of expertise.

The positive results consisted of decreases in hospitalizations, quicker recovery and reductions in unplanned hospitalizations. No significant changes were recorded in emergency department visits or hospital admissions and in health-related quality of life. Family members reported overall high satisfaction scores with digital health interventions, and parents perceived availability of digital health to be “very important” in assisting them in managing their child’s condition at home [77]. Some of the programmes actively involved families in the development, testing and refinement of the intervention. The results were encouraging, with the development of educational materials that were acceptable and useful to parents [76]. An important issue in telemedicine is the evaluation of the technologies available to families. A response bias may be linked to the gap existing between Caucasian and minority populations. Some interventions supplied equipment or internet services to families [78]. Technical issues, affecting digital health interventions, consisting mainly in disruption in connectivity did not alter overall satisfaction for clinicians, management and patients [79]. Even if most of the studies reported a favourable feedback, digital health was not always appropriate. Therapists had difficulty engaging with younger children with hearing loss during videoconferencing appointments, social workers preferred in-person appointments to facilitate a personal connection with patients, and some parents considered that face-to-face demonstrations of clinical skills were mandatory for optimal treatment fidelity [70]. Funding is an issue affecting digital health because of the restrictions related to reimbursement. Up to 36% of booked telehealth appointments are not billed by a faulty system [80].

The use of digital health to care for children with medical complexity is a modern way to connect patients, some in remote areas, to expert care from health professionals while lowering the expenses and avoiding potential harms of the hospital-based care system.

6. Family caregivers for home care recipients with advanced non-cancer diseases

Conditions as congestive heart failure, end-stage renal disease, chronic obstructive pulmonary disease, liver failure and dementia represent the non-malignant life-threatening illnesses which require a complex home care. The different trajectories of functional decline are useful for the home care providers, helping them to tailor strategies and make a better plan of care. Lunney identified four theoretical trajectories of chronic illnesses: sudden death, cancer death or terminal phase, death from organ failure and frailty and dementia [81]. In cancer, the clinical status of the patients is acceptable until the disease does not respond to the treatment and the rapid decline makes easier to predict the terminal stage. In non-oncological chronic diseases, the trajectory is different with several deteriorations and improvements of the clinical state and a slow decline line. In dementia or general frailty, the illness trajectory has a gradual and prolonged decline. The trajectory of renal failure disease may be that of a steady decline, with the rate of this decline varying according to the underlying renal pathology and other comorbidities [82]. Sometime the issues of caring for patients with non-oncological illnesses is more difficult than for patients with cancer because the prevalence of symptoms is higher and there is a prolonged trajectory of decline.

Patients with non-oncological illnesses as opposed to patients with cancer are older and have many comorbidities and cognitive impairment. The barriers in home care assistance for the recipients with non-cancer illnesses include less predictable trajectory, the lack of knowledge regarding the care needs of end-stage period, the low use of and late referral to palliative care [83], the possible overwhelm of the palliative care services, the necessity of knowledge in different specialties and the necessity of training in the areas of symptom control [84], and prognostication in non-malignant disease tends to be less accurate than in cancer [85]. These recipients require a multidisciplinary home care team, because they have a multidimensional area of caring. The involvement of the family caregivers is valuable and implies management of digestive problems, balance of fluid and food intake, nutritional status and care of bedsores. Needs such as: fall risks, self-care capacity, instrumental activities of daily living, dementia, fecal and urinary incontinence are difficult to solve [86]. Compared with cancer patients, the non-malignant patient's needs are more complex: moderate and severe neurological issues, psychiatric problems, needs for assistance with defecation and bladder function and moderate and severe deterioration of vigilance (somnolent and comatose) [87]. A higher proportion of non-cancer patients was discharged and died at home, and the proportion of readmitted patients to the hospital was less than for oncological patients [87].

7. Integration of basic palliative care in the Romanian general practice

The majority of the incurable ill patients can be treated within primary care health professionals, and 10–15% will be in need of specialist palliative care (PC) [88]. Family physicians' role in primary palliative care and cooperation between specialist palliative care services should become stronger. Palliative care has expanded since its relevance for non-oncological diseases has been widely acknowledged and integration of PC at an earlier stage in the disease process has been shown to be beneficial [89].

The real palliative care extent in primary care is underestimated since the estimates of an average care by family doctor for three to four patients with PC needs per quarter do not appropriately reflect care for patients with non-oncological conditions [90]. There is a predominance of non-oncological chronic multi-morbid

patients such as cardiovascular or pulmonary diseases in need of PC in general practice, and these recipients require a valuable involvement of the informal caregivers from their families [91]. Despite the widely acknowledged importance of family doctors' engagement in primary PC [92], difficulties and even barriers were identified in the delivery of home-based PC in practice in our country as well as in the high-developed countries [88].

In a project developed in Romania in 2013–2016 by the Hospice of Hope, Brasov, with the financial support from the Swiss contribution to the enlarged European Union, barriers and ways to integrate a pilot model of basic palliative care in the healthcare system were identified [93]. Hospice of Hope, Brasov, is a Romanian non-profit organization, Centre of Excellence in PC for Eastern Europe and Central Asia, and one of the seven globally recognized models of palliative care. It develops palliative care at national and international levels through information, by improving the legislation in the field and through educational programmes dedicated to professionals, recipients of PC and family as provider of home-based PC.

The impediments in the delivery of primary palliative care refer to:

- Structural barriers (e.g. family physicians and community nurses' shortage due to high emigration rates of junior doctors and nurses and unequal distribution of primary care offices in rural versus urban areas)
- Knowledge barriers (e.g. lack of skills and clinical routine in providing PC, practical obstacles in palliative training due to distance from the training centre and lack of substitute in the medical office)
- Service barriers (e.g. lack of palliative care services for home care in some regions of the country, insufficient reimbursement of these services in the public healthcare system).

Nationally, approximately 150,000 people with oncological diagnosis and other incurable diseases need home-based palliative care every year, but less than 7% of them benefit in a timely manner. During the project, the model of basic palliative care was tested in 4 pilot counties, on 26 family doctors trained for 6 months to provide palliative services to a number of 138 oncological patients treated at home. A guide of basic palliative care was developed and offered to the family doctors, contributing to the replication of the model in other counties and to the training of the community nurses and informal caregivers.

Adopting the model of providing basic palliative care through family doctors can increase in the coming years, contributing to the palliative care needs assessment after diagnosing the incurable disease, not only in the end of life, and through specific interventions to increase the quality of life of these recipients in the community.

Basic or primary palliative care includes the following:

- Communicating the diagnosis and reasonable possibilities of treatment at home, identifying the treatment goals in agreement with the recipient and his/her family, controlling the symptoms of low to medium complexity and maintaining the functions and capacity for self-care
- Involving the family caregivers in the home care, in making decisions regarding the treatment, and preferred place of death
- Treatment of symptoms due to chemo- and radiotherapy and their complications

- The burden of care assessment and interventions to protect the health of the family caregiver
- Clarification of aspects related to obtaining socioeconomic rights for people diagnosed with incurable disease

The family caregivers' role in the management of spiritual pain caused by feelings of helplessness of life with disease is essential. It needs to be recognized and addressed by the primary healthcare professionals, offering psychological and spiritual support and elevating the self-esteem of recipient from the stable stage onwards.

Providing home-based palliative care that maximizes the self-determination of patients depending on patient-centred needs and preferences through communication is important. Prioritizing the home care needs may differ depending on individual perspectives which make mediation of different opinions through open communication between home care multidisciplinary team, recipient and family caregiver to be pivotal. With increasing aging population, keeping living and functioning the chronically ill on long term with current means of treatment, it is anticipated that the proportion of people who should receive PC will increase considerably [89, 94, 95]. An intervention package for the primary PC, such as that proposed in Germany in a study protocol of a research study of the organizational health services with three mixed methods [88], tailored to each country in its context of healthcare, should enable primary healthcare professionals to provide primary PC to their recipients in accordance with their professional standards that address barriers and involve family caregivers in the home care of loved ones.

8. Future family doctors' resourcefulness to meet the societal changes and the burden of home care in the modern family: academic medicine perspective

Due to demographic changes, with increasing number of people in need of care and societal changes (decreased family size, more geographically dispersed families, erosion of barriers that previously could have kept couples together during difficult times, erosion of bonds between family generations, increasing number of people living alone), informal care structures are affected by considerable challenges [96]. In addition, the increase of urbanization, the rural-urban movement and the international migration profoundly affect the family structure and its involvement in providing long-term home care and providing a supportive environment.

Family caregivers involved in home care often face the challenge of balancing caregiving and job responsibilities. Involving older adults in caring for the elderly and children with disabilities and integrating informal caregivers, such as friends and neighbours, is valuable and requires strong intergenerational solidarity in the community. However, in low- and middle-income countries, chronic patients who seek support for maintaining independence and quality of life are often faced with a lack of health and social services, especially in rural areas, or in-home care with poor quality.

The availability of both in-home services (such as personal care and home healthcare) and community services (such as day programmes, congregate meals and social centres) enables a growing percentage of older recipients to delay or even avoid institutional care [97]. The shortage of formal and qualified caregivers presents a challenge for the future regarding the structure and organization of long-term care for most countries. The increasing number of care-dependent people leads to a high economic burden for most healthcare systems [98]. In order to support and facilitate family caregivers in their role of nursing, it is important to

be carefully coordinated and their burden of care assessed by the comprehensive trained primary care health professionals.

Family physicians need a set of specific competences to perform well in inter-professional teams, and these competences should be achieved by graduating from a medical school [99]. Most medical schools have components of communication skills in the curriculum, but there are no clear standards for competence in communication skills, and the approach of interprofessional communication in the care team is limited. Beyond standardization of communication skills curricula, it is also necessary to verify primary care physicians' proficiency in interpersonal and interprofessional skills.

In some residency programmes, residents receive 360-degree evaluations which go beyond the typical assessment performed by the supervising attending physicians [100]. Such evaluations help residents better understand how they are viewed by those with whom they work and by those for whom they care. Family medicine residents' assessments are requested from the attending physicians and nurses and from the patients themselves who complete questionnaires from their perspective on the interaction of the resident doctor with the recipient and his family, obtaining 360-degree feedback from all those who have interacted with the resident functions as a valuable teaching tool in family medicine residency programme. Observations gained from multiple perspectives are believed to be more valid than individual opinion, and sharing them will likely have a positive effect on the development of physician trainees in family medicine and his future involvement in home care provision.

Academic medicine seeks to enhance training introducing new curricular areas dedicated to the development of interprofessional communication skills and resourcefulness in managing difficult circumstances in medical profession [101]. Future primary healthcare professionals, especially family doctors, should provide more comprehensive home care to their recipients, maintaining their independence and offering expected years of life free of disability.

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