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CHAPTER 2

Conceptual and theoretical framework

This chapter presents concepts and theories relevant to this thesis, which serve as the conceptual frame for addressing the central question and sub-questions of this research. First, we describe the definition of health, and how it relates to current conceptualisations of one's state of health and wellbeing, with a focus on chronic diseases. We then proceed with a deliberation on the organisation and functions of a health system as they relate to the delivery of chronic care and strategies for the management of chronic diseases. The chapter concludes with a presentation on the relevance of integration in chronic care, particularly at primary care level, and the necessary adaptations for local health systems in resource-limited settings to deliver responsive quality care for chronically ill patients.

DEFINING HEALTH AND CHRONIC DISEASE

According to the World Health Organization constitution health is defined as *"a state of complete physical, mental, and social wellbeing, and not merely the absence of disease or infirmity"* [1]. However, the applicability of this definition for people living with chronic diseases has been subjected to considerable debate ever since it was adopted for use in 1948. In these debates, scholars argued for the need to modify the definition to a more encompassing one that would reflect the incurability and longevity of chronic diseases [2-4]. It was not until the 1986 Ottawa Charter [5] that such a refined definition on health emerged in which the concept of resilience was added:

"To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment. Health is therefore seen as a resource for everyday life, not the objective of living...a positive concept emphasizing social and personal resources, as well as physical capacities."

During the Ottawa Conference, the WHO, national governments, international organisations and conference delegates committed to promoting health for all by year 2000 [5]. Health promotion, defined as the process of enabling people to increase control over and improve their health, was considered critical for people living with chronic diseases [5]. It expanded the previous notion of health promotion in public health for the containment of acute and other infectious diseases to also encompass measures that would support a patient's adaptation to changing circumstances.

In 2011, delegates in an international health conference with chronic diseases experts in Netherlands, further challenged the still-in-use definition of 1948, and proposed a new one. In their view, health is *"...the ability to adapt and self-manage in the face of social, physical, and emotional challenges"* [4]. Huber et al's "positive health" definition maintains the three domains of health, i.e. physical, mental and social, but emphasizes that health can (still) be realised by making necessary adaptations, and facilitated

through providing patients with the requisite knowledge and skills of how to manage their health condition over time [4]. For instance, when confronted with physiological stress, the human body is capable of mounting a protective response and reduce the potential for harm [4]. Similarly, individual's develop internal mechanisms to facilitate their coping and recovery from strong psychological stress [4]. The social health domain refers to people's capacity to fulfil their potential and their ability to manage their life with some degree of independence despite a medical condition [4]. By successfully adapting to an illness, people would be capable of working or participating in social activities, and feel healthy despite their limitations [4, 6].

Unlike acute diseases with known causative agents, the causes or determinants of ill-health for chronic diseases tend to be broad and complex, including genetic, biological, environmental, cultural and behavioural factors, and lifestyle choices [7, 8]. Behaviours that are known to be unhealthy such as smoking, excessive alcohol consumption, physical inactivity, and food intake that is high on cholesterol, sugar or sodium, are common risk factors for the development of cardiovascular diseases, diabetes, and respiratory diseases [8, 9]. Furthermore, an individual's health status is influenced by other ecological factors such as an individual's socio-economic status (e.g. household income and affordability of healthy diets), housing conditions (e.g. ventilation, safety), or ease of access to amenities (e.g. distance to health facility, transport infrastructure) [7].

Intervention measures to promote healthy lifestyles, detect, and manage chronic conditions require collaborative efforts from both the health and non-health sectors [10]. The focus of this thesis is on the responsibilities and organisation of the health sector. In the next section, we discuss how healthcare systems are generally organised in sub-Saharan Africa and what the delivery of chronic care requires.

ORGANISING HEALTH: SUB-SAHARAN AFRICAN HEALTH SYSTEMS AND ORGANISATION OF CHRONIC CARE

Health systems are required to constantly adapt and respond to changes in the disease patterns and health needs of the population they serve. A health system is defined as "*all activities whose primary purpose is to promote, restore and/or maintain health*" [11]. It is a collective of institutions, people, and resources that have been organised in accordance with established policies, and with the objective to improve the health of the population [11]. In most sub-Saharan African health systems, health services are organised into three interlinked levels; primary, secondary and tertiary care. The primary care level, which also includes community-based health services, serves as the entry point for people into the health system [12]. In recent times, there has been a strong call to see community health systems as distinct sub-systems in overall health systems [13]. At this level, people can receive basic healthcare and

diagnostics and, if necessary, be referred to higher levels of the system for more specialised care. A significant portion of sub-Saharan Africa's population resides in rural areas, where primary care services are often the only services available [14]. These services are provided in dispensaries, health centres or health posts operated by mid-level health professionals such as clinical officers, medical health assistants, nurses, and are supported by a community health workforce. The secondary level of care is comprised of district hospitals and other referral institutions at sub-national level, where specialised services are provided including surgical and inpatient care, as well as referrals from primary care facilities [15]. The health workforce at this level consists of specialist physicians, senior health managers and programme coordinators, working together with other mid-level health professionals [15]. The tertiary level of care is the top-most health service tier usually at national level, where referral and specialist services (such as cancer treatment centres, cardiology, haematology, endocrinology, psychiatry) are provided in more advanced care institutions [15]. These include public teaching and referral hospitals, private for-profit hospitals, and private not-for profit hospitals run by charitable or faith-based institutions. At national level, the Ministry of Health is mandated by the government to undertake functions such as policy formulation, legislation, standardisation, and financial allocation for health services [11]. Based on this stewardship function, they liaise with other line ministries and institutions supporting health to generate revenue towards health, whilst coordinating service delivery functions.

The high costs associated with delivering long-term care for chronic conditions, in terms of treatment regimen, diagnostics, and advanced medical technologies, require governments to allocate sufficient funds, yet many sub-Saharan African health systems struggle to finance national health budgets [10]. The majority of African governments' health financing is below recommended targets (less than 15% of annual budgets) [16], with high dependency on external-donor funding, and exacerbated levels of patient out-of-pocket spending on health [17]. A further concern is the current poor state of health infrastructure in this region, characterised by limited physical space and lack of basic amenities such as water and electricity to operate health facilities [10]. Also the tendency to invest in NCDs at higher levels (secondary and tertiary), puts into question the level of preparedness to deliver chronic services at primary care level [12].

Delivering chronic care further requires the right combination of healthcare professionals with the appropriate skills-set, and there is more demand for positive patient-provider relations during their interactions [18]. However, the global health workforce crisis continues to place immense strain on health systems worldwide, with greater impact on sub-Saharan African countries, where the provider-patient proportions are remarkably low [19]. Furthermore, healthcare providers working conditions constituted by heavy workload, understaffing, and poor remuneration, have a negative impact on staff retention and motivation, which compromises

the quality and standards of care provided [10, 19]. Multiple interventions are thus needed to strengthen health workforce performance. For instance, providing training to advance healthcare providers technical know-how, balancing recruitment and posting of healthcare professionals, and provision of resources such as protocols and job-aides to support clinical care [11]. In some settings, task-shifting initiatives have been experimented with, where some health functions are delegated to lower cadre staff and non-physician providers in an effort to meet service-provision gaps [20]. However, contextual differences and population needs could, to a greater extent, determine staffing approaches and policies to be effected.

The future of chronic care largely depends on the transformation of sSA health systems, notwithstanding the numerous challenges and the urgent need for implementing low-cost interventions, which cover diverse patient populations. Such transformations could include prioritizing primary prevention as a key public health strategy, in order to stabilise the upsurge of chronic conditions and control healthcare spending [21]. Second, the provision of comprehensive services at the first-line of care to cater to the multiple care needs of chronically ill patients is critical [22]. This approach is engrained in the principles of primary healthcare [12, 23], which advocate for universal access and equity, and promote community participation and inter-sectoral collaboration in health. While there is no clear-cut approach to implementation of these policy measures, it raises the question as to what extent local health systems are prepared to deliver chronic care at the primary care level.

APPROACHES PROMOTED FOR CHRONIC CARE: MODELS OF CARE AND SELF-MANAGEMENT SUPPORT

The complex and partially unpredictable nature of chronic diseases requires interventions that cut across the different spheres of a patient's life, as does their condition [24]. Let us take a brief moment to reflect on these patients; an elderly cancer patient, a farmer with epilepsy, a school teacher living with HIV, or a retired civil servant with stroke. A typical day for them involves dealing with symptoms, taking medication, working to fend for themselves, and engaging in family and social obligations. These are patient's daily realities, and by virtue of living with these conditions, they are their own 'health managers' [25]. Therefore, taking cognisance of the important role of patients in managing their own health, and how their condition cuts across all facets of life, the application of a holistic approach to patient care and support becomes critical. This is captured in the patient-centred approach which forms the foundation for chronic disease management [26].

The Institute of Medicine defines patient-centred care as *"providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions"* [27]. This approach challenges

the traditional and paternalistic view of the patient-clinician relationship, in which patients are mostly passive and less engaged in decision making processes [28]. It calls for a transformation of the patient's role from a passive to a proactive and integral member of the healthcare team, and promoting patient autonomy in healthcare decisions [28]. Ultimately, the aim is to arrive at a collaborative partnership between clinicians and patients, in which patients are empowered with the appropriate tools and resources that will position them as better self-managers [29, 30].

The Chronic Care Model (CCM) epitomizes how patient-centred care principles could be instilled in a health system, proposing various system conditions to achieve productive interactions between patients and providers of care [31]. System conditions have been categorised into the following elements: delivery system design, decision support, clinical information systems, and self-management support, with supportive instructions for each to guide the delivery of high-quality chronic care (see Table 1). The element of self-management support refers to a range of resources (e.g. patient education, tools and skills for self-management) that healthcare teams are expected to provide to patients to empower and enhance their capacity to manage their chronic conditions [31]. In addition to these system conditions, a strong link is promoted between the healthcare team and community entities (such as community programmes and patient organisations) to allow for mobilisation and tapping of resources to meet patient needs beyond the clinic environment [31].

Studies that have evaluated implementation of this model have demonstrated improved patient satisfaction with health services, and created patients who are more engaged in care and aware of their rights [32, 33]. However, the model is premised on a well-functioning health system and the experiences it records are heavily drawn from high-income settings [32-34]. In response, in 2002 WHO further adapted the chronic care model to enable its transferability and use in other, less advanced settings [35]. The Innovative Care for Chronic Conditions (ICCC) framework applies a systems approach whereby the chronic care environment (actors and institutions) are organised into three interactive levels and guided by a set of common principles [35]. The micro-level consists of patients and family caregivers, while health organisations and community partners constitute the meso-level. The macro-level focuses on a positive policy environment responsible for legislation, leadership, policy integration, financing and allocation of human resources [35]. An add-on to the ICCC framework as compared to the chronic care model is the recognition of community partners who support with mobilisation and coordination of resources, and provision of complementary services [35]. Healthcare teams are expected to promote continuity and coordination of care, promote preventive measures, and support self-management [35]. These interactions could arguably result in an informed and empowered patient, and generate better outcomes for chronic conditions. Based on Wagner's CCM and the WHO ICCC framework [31, 35], there are a number of common principles proposed for chronic disease management; that is, the need for patients' active engagement in

care; the presence of a multidisciplinary team supporting patients in health facilities and home settings, and providing them with resources in their self-management. However, the transferability of these principles in contexts where clinical care is sub-optimal and patients largely depend on care outside formal healthcare systems (e.g. family and community caregivers) remains under studied.

What is perceived to be the role of families and communities in supporting patient's self-management? Families are believed to play a crucial role in supporting patient day-to-day care needs due to their proximity to the patient. In the sub-Saharan African context, family members are customarily obliged to take up several responsibilities, that is, to be breadwinners for their children and extended family, cater to the needs of the sick, and participate in communal activities when called upon [36]. As witnessed during the HIV epidemic, family caregivers continue to absorb many responsibilities including providing palliative and rehabilitative care to ailing patients, often lacking within primary care settings [36]. In communities, the engagement of community volunteers (CHVs) in health has been a long-standing practice, which led to the implementation of numerous community-based health programmes, and more recently, in delivering interventions targeting chronic patients [13]. However, the longstanding practice of engaging CHVs in such programmes has its share of challenges including lack of proper incentives mechanisms, a failure to recognise and meet their expectations e.g. career progression and professionalization of this cadre, while there is limited and varied practice in the reconfiguration of CHVs in formal/national health systems [37-39]. Due to the deficiencies in health systems and human resource challenges faced in most sSA, community caregivers serve an important role in under-resourced health system contexts and will continue to be key actors in driving the primary healthcare agenda, as endorsed in the Alma Ata Declaration of 1978 [23].

Table 1 — Principles guiding implementation of the Chronic Care Model (CCM)*

MODEL ELEMENT	GOAL	PRINCIPLES PROMOTED
1. Health system	Create a culture, organization and mechanisms that promote safe, high quality care	<ul style="list-style-type: none"> • Visibly support improvement at all levels of the organization, beginning with the senior leader • Promote effective improvement strategies aimed at comprehensive system change • Encourage open and systematic handling of errors and quality problems to improve care • Provide incentives based on quality of care • Develop agreements that facilitate care coordination within and across organizations
2. Delivery system design	Assure the delivery of effective, efficient clinical care, and self-management support	<ul style="list-style-type: none"> • Define roles and distribute tasks among team members • Use planned interactions to support evidence-based care • Provide clinical case management services for complex patients • Ensure regular follow-up by the care team • Give care that patients understand and that fits with their cultural background
3. Decision support	Promote clinical care that is consistent with scientific evidence and patient preferences	<ul style="list-style-type: none"> • Embed evidence-based guidelines into daily clinical practice • Share evidence-based guidelines and information with patients to encourage their participation • Use proven provider education methods • Integrate specialist expertise and primary care
4. Clinical information systems	Organize patient and population data to facilitate efficient and effective care	<ul style="list-style-type: none"> • Provide timely reminders for providers and patients • Identify relevant subpopulations for proactive care • Facilitate individual patient care planning • Share information with patients and providers to coordinate care • Monitor performance of practice team and care system
5. Self-management support	Empower and prepare patients to manage their health and health care	<ul style="list-style-type: none"> • Emphasize the patient's central role in managing their health • Use effective self-management support strategies that include assessment, goal-setting, action planning, problem-solving and follow-up • Organize internal and community resources to provide ongoing self-management support to patients
6. Community	Mobilize community resources to meet needs of patients	<ul style="list-style-type: none"> • Encourage patients to participate in effective community programmes • Form partnerships with community organizations to support and develop interventions that fill gaps in needed services • Advocate for policies to improve patient care

*Adapted from the MacColl Institute for Healthcare Innovation¹.

¹ For additional information; http://www.improvingchroniccare.org/index.php?p=Model_Elements&s=18

The recognition of community caregivers in chronic care has seen the emergence of several community-based initiatives such as peer-led or expert patient self-management programmes [40, 41]. Within these initiatives, lay-leaders and fellow patients collectively engage in education, counselling, problem solving and skills training, to empower patients and raise their self-efficacy to manage conditions [40, 42]. Self-efficacy, a concept derived from Bandura's social cognitive theory [43], refers to "*beliefs in one's capabilities to organize and execute the courses of action required to produce given attainments*". Applied to chronic care, it refers to an individual's confidence in the ability to perform tasks and make necessary adjustments to manage their conditions [6, 26]. This theory has been applied in several self-management programmes, which aim at raising patient confidence to take control of their overall wellbeing and improve health outcomes [41, 44]. Reviews and studies evaluating the effectiveness of self-management programmes highlight variations in improvements in patient outcomes – with most reported studies coming from high-income settings [41, 44, 45]. This warrants the need to assess what sort of self-management programmes exist for patients with chronic conditions, especially in resource-limited settings in sub-Saharan Africa, and what impact do they have on health outcomes.

Coordinated care is an essential feature for the efficient delivery of chronic care [31]. Chronically-ill patients require a range of services, which may compel them to visit different clinicians or specialists, and move across the referral chain [22]. This calls for instituting mechanisms that allow for communication and exchange of information across clinicians and systems. The absence of a coordinated approach can lead to fragmentation in care and poorer patient management [31]. Hence, the need for integrated approaches to meaningfully coordinate the limited resources and activities of various healthcare teams and departments within and beyond a healthcare system.

THE RELEVANCE OF INTEGRATION IN CHRONIC CARE

Integrated care provides a possible solution to coordinate care more efficiently, especially for patients with complex needs, which span across multiple disciplines. Despite the growing recognition of integrated care in international health discourse, its meaning and application varies widely. Firstly, the multiple roles and perspectives of actors that form a health system contribute to the complexity of providing integrated care. Secondly, there is limited conceptual clarity on integrated care, possibly as a result of this complexity. There have been different attempts to bring clarity on this important concept in chronic care. For example, WHO defined integrated care as "*the provision of seamless and coordinated healthcare to ease patients or service users' navigation across different levels of care*" [46]. From a healthcare provider and management perspective, integration may imply bringing together different clinical services, delivered by a multidisciplinary team, and facilitating the efficient use of

equipment, supplies, space and personnel [46, 47]. At the policy level, integration efforts strive for harmonisation of policies and financing mechanisms, and to promote collaboration across the cure and care sectors [48]. Overall, integration efforts aim at improving efficiency in the coordination and delivery of healthcare services, enhancing quality of care, and maximising access and coverage, and improving user satisfaction.

There are various frameworks that describe the different dimensions of integrated care that is, the level of integrating health services ranges from linkages, coordination to full integration system, while the breadth of integration refers to the capacity to provide health services at the same level of care (horizontal integration) or at different levels of the healthcare systems (vertical integration) [47-50]. This thesis applies the integrated care framework developed by Valentijn et al [51], as it combines the concepts of integration with primary care elements, across the various levels of a health system. We selected this framework as it allows the closer examination of primary care concepts such as continuous comprehensive care with linkages at different tiers of the health system, and interrogates the various dimensions of integration at the micro, meso, and macro level. As illustrated in Figure 1, this framework provides a heuristic to assess the full spectrum of integration.

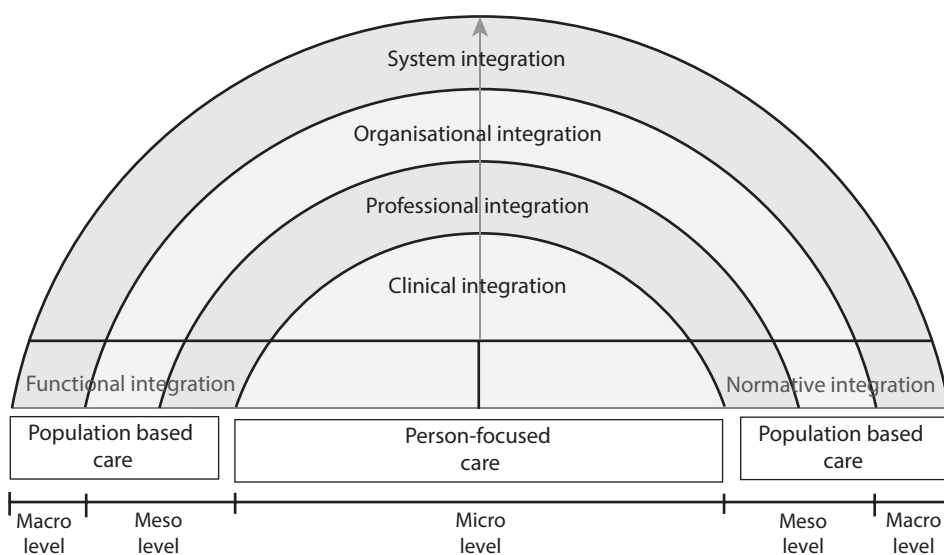


Figure 1 — Adapted from Valentijn 2013: A comprehensive conceptual framework based on integrative functions of primary care

Clinical integration, which also refers to service integration, is the provision of a continuum of services and focuses on the patient-provider interaction, aimed towards meeting holistic needs of a patient, in a single visit [51]. In meeting patient's needs, the framework recognises the overlap between health and social problems, which necessitate the need to link both the health and social system [51]. For instance, most chronically ill-patients would benefit from interventions that meet their biomedical needs (e.g. treatment and good nutrition), psychological (emotional and mental wellbeing), and social needs (caring environment). The framework further distinguishes the dimensions of care, where person-focused care, also defined as patient-centred care elsewhere [18, 24], is the delivery of care that is responsive to patient needs, values and preferences, while population-based care characterises health-related needs of a defined population, such as those socially disadvantaged or living with comorbidities [51]. The overall goal is to ensure patients access to comprehensive, continuous, coordinated care at their first-level of care.

Achieving the above is highly dependent on the planning and decision-making processes of healthcare providers and managers. Typically, in most African health systems, priority setting, resource allocation, and policy decisions are concentrated at the centre or national level, hence taking a top-down approach [14]. Valentijn's framework examines the governance mechanisms of actors/agencies to distinguish the locus of power, which could facilitate or hamper efforts towards organisational integration [51]. To deliver population-focused care, this form of integration requires the collective responsibility and actions of organisations to provide comprehensive services across the entire care continuum [51]. Organisational entities include health ministries, private sector partners, social services, and development sectors. Inter-organisational integration would further depend on the extent of shared-decision making and duration of commitment amongst these entities. In segregated cases, organisations function as independent entities and relations are more contractual due to market competition [51]. In full integration contexts, the governance mechanism is hierarchical with top-down coordination of organisations (such as mergers and acquisitions), although most common in high income settings [51]. The role of health ministry representatives at the meso-level could be viewed as that of providing stewardship in the linkage and coordination of inter-organisational activities (network management).

At the macro-level, system integration requires tailor-made combination of structures, processes and techniques to fit the needs of people and populations across the care continuum [51]. However, due to the specialisation of disease-focused interventions, such as HIV or diabetes stand-alone clinics, and the delivery of those services across different levels of care (vertical integration), it results in fragmentation of services and threatens the holistic perspective of primary care [51, 52]. Horizontal integration occurs when organizations or units at the same stage in the process of delivering services come together [47, 51]. To minimise the fragmentation of services for

chronically-ill patients, both vertical and horizontal approaches are needed, together with the promotion of inter-sectoral partnerships.

In sub-Saharan Africa, the practice of integration is varied, in for instance merging activities of distinct/disease-specific programmes, or pulling a package of activities of distinct programmes at front-line services. There have been documented lessons on experiences of combining or merging HIV services with activities of other disease programmes, like NCD services, and with promising results [53-58]. For example, in South Africa the formulation and rollout of a nationwide integrated chronic disease management policy, which emphasizes synergistic efforts in delivering coordinated care for multiple chronic conditions in primary care settings [59]. In summary, the degree of HIV and NCD service integration ranges from integrating selected activities (such as screening, health promotion, treatment and referral), to providing comprehensive services across the care continuum [55, 58]. Factors facilitating integration include the organisation of health services for HIV and NCD under the same roof or in a one-stop model; offering multi-disease screening at community and facility settings with early initiation to care; and organising a robust system to track and monitor referred patients (appointment reminders and link patients lost to care) [57, 58]. Factors that hamper integration efforts are systemic and inter-relational. For instance, the fear of losing one's professional identity when vertical/specialised programmes are merged, and inadequate financing to facilitate the coordination of various programmes [52]. Studies have also shown the importance of contextual factors within local health systems on the ability to achieve integration, ranging from physical obstacles (limited clinic space) to power dynamics amongst healthcare professionals [60, 61]. Hence, it is crucial to carefully study and identify what works under which conditions when it comes to integrated care.

In conclusion, this chapter has elaborated various concepts and theories that are relevant in investigating how local health systems are structured, what interventions are needed, and what the role of the multiple actors and sectors in designing and delivering chronic care within primary care level in resource-limited settings. Figure 2 below shows how the different key domains of interest, with reference to the chapters that will be presented in the thesis are linked. In the examination of chronic care provision and patient self-management in Malawi, we will closely examine the individual care practices and factors within the home and clinic environment that shape patient behaviours. At a system level, we are interested in the interface between actors in the patient support network and patients themselves, and the structures and processes in place that shape how chronic care is designed and delivered in a resource-constrained setting.

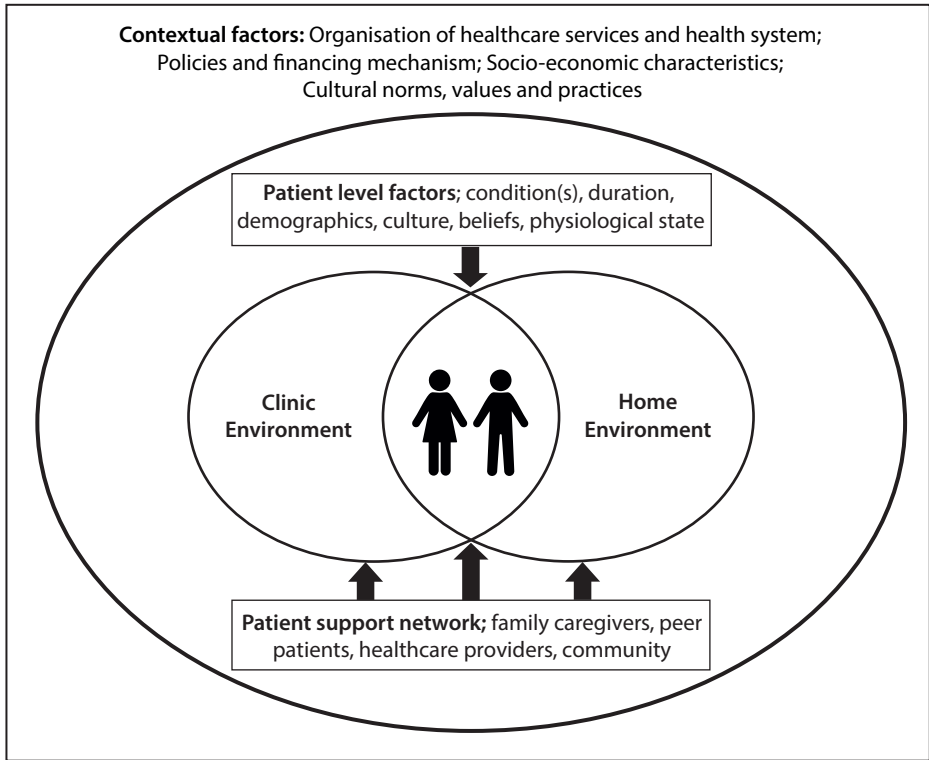


Figure 2 — Thesis concepts and domains of interest summary

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