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Integrated care for healthcare sustainability for patients living with rare diseases

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Abstract
The increasingly complex and multidimensional care request, combined with the presence of increasingly aware and demanding patients, accentuates the need for new strategies to preserve health systems economic sustainability. Therefore, integration mechanisms reveal an essential condition for ensuring continuity of care. The paper reviews the main literature available on the integration of heal services and relates it to rare diseases. The literature identifies several system levers for the effective design and implementation of integrated care frameworks, namely: political support and commitment, governance, stakeholder engagement, organisational change, leadership, collaboration and trust, workforce education and training, patient empowerment, financing and incentives, ICT infrastructure and solutions, monitoring and evaluation system.

Key words
- integrated care
- rare diseases
- organizational change
- patient empowerment

INTRODUCTION

The world has changed over the last 30 years: urbanization, ageing and globalized lifestyle changes combine to make chronic and non-communicable diseases – including depression, diabetes, cardiovascular disease and cancers – and injuries increasingly important causes of morbidity and mortality. The growing prevalence of chronic diseases and population aging – are placing a heavy burden on health systems, individuals, families, businesses and governments. The World Health Organization (WHO) estimates that an increase of 10% of chronic diseases is associated with a reduction of 0.5% of annual economic growth [1]. On other hand, in the light of scientific and technical developments, people live for longer. The children born with complex conditions are now living to adulthood, while those with learning disabilities and other groups have lifelong needs. All these people need continuous care and support, and the right systems and resource to enable that. In addition, the renewed socio-economic, cultural and epidemiological conditions have undermined health systems, highlighting the weaknesses of the traditional way of understanding and organizing the health system. In fact, although health systems are also a reflection of a globalizing consumer culture, however do not provide an adequate response to need and demand, and that they are driven by interests and goals that are disconnected from people's expectations. In fact, the traditional approaches to care focus on individual diseases and are based on a relationship between an individual health/social care service-user and a single health/social care professional. Then, current health systems amplify the potential for care fragmentation between different professionals and care organisations.

Thus, the increasingly complex and multidimensional care request, combined with the presence of increasingly aware and demanding patients, accentuates the need for new strategies to rationalize resources, organizational methods and use of services, which preserve economic sustainability by acting on waste and on inefficiencies. In this scenario, the identification of integration mechanisms reveals an essential condition for ensuring continuity of care.

MATERIALS AND METHODS

The paper reviews the main literature available on the integration of heal services and relates it to rare diseases. Several medical databases and additional information resources were utilised and included government documents, reports from international bodies such as the World Health Organisation, EURORDIS and academic studies. The key search terms were integration of care and rare diseases, from 2000 through January 2018. Articles of interest were reviewed to determine which were relevant and subjected to analysis. Selected papers were later used to extrapolate the most relevant messages about integration of healthcare services for rare diseases.

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RESULTS

The importance of integration is emphasized by the WHO global strategy on people-centred and integrated health services. The strategy calls for shifting the way health services are funded, managed and delivered, and proposes five interdependent strategic directions that need to be adopted for health services to become more people-centred and integrated *(Figure 1)*. The five interdependent strategic directions include:

1. empowering and engaging people;
2. strengthening governance and accountability;
3. reorienting the model of care;
4. coordinating services;
5. creating an enabling environment.

Our review highlighted that there is no unifying definition or common conceptual understanding of integrated care, which is most likely a result of "the polymorphous nature of integrated care itself" [2]. The concept of integrated care is strongly shaped by perspectives and expectations of various users in the health system, making a unified definition difficult.

"Integrated care" is a term that reflects a concern to improve patient experience and achieve greater efficiency and value from health delivery systems. The aim is to address fragmentation in patient services, and enable better coordinated and more continuous care. In effect, the perspectives that construct the concept are likely to be shaped by views and expectations of various stakeholders in the health system. The literature reviewed offers a range of examples of how integrated care might be adopted in practice.

The rarity and complexity of rare diseases highly condition the availability of knowledge about their impact on patients' and families' life expectancy, daily life and autonomy. Indeed, patients affected by a particular rare disease are few and spread geographically. It is therefore clear that RD have special requirements which distinguish them from other complex or chronic diseases. They are not only complex but also frequently unpredictable, requiring often stays in hospital, specialist care and access to professional and medical knowledge not always available or may not even exist. The knowledge on the impact of rare diseases on patients' functionality remains a challenge within the national systems, which often entails an inadequate recognition and inappropriate compensation for disabilities, exacerbating the social and economic vulnerability of people living with a rare disease and of their families. Several studies, conducted by patient's organisations, have demonstrated the serious impact of rare diseases. Results of the first European-wide survey on the everyday impact of rare diseases – "Juggling care and daily life: the balancing act of the rare disease community" [3], conducted by EURORDIS survey initiative, Rare Barometer Voices and involving 3000 patients and carers [4, 5] – put into evidence the serious impact of rare diseases and the need for integrated care.

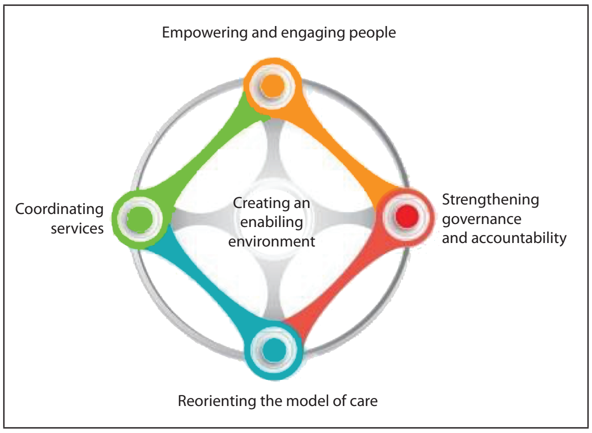

Figure 1
Five interdependent strategic directions to support people-centred and integrated health services (Reproduced with kind permission from WHO – WHO Global Strategy on People-centred and Integrated Health Services; 2015 [6]).

DISCUSSION

The WHO global strategy on people-centred and integrated health services identified five strategic directions.

Put together, the five strategic directions represent an interconnected set of actions that seeks to transform health systems to provide services that are more people-centred and integrated. However, for each specific context, the exact mix of strategies that will be used needs to be designed and developed, taking into account local contexts, values and preferences. The benefits of a people-centred and integrated approach are well documented: increased delivery efficiency, decreased costs, improved equity in uptake of service, better health literacy and self-care, increased satisfaction with care, improved relationships between patients and their care providers, and an improved ability to respond to health-care crises [6]. Recognizing that health systems are highly context-specific, it is clear that there is no a single model of people-centred and integrated health, instead several strategic directions to better coordinate care around people's needs. In view of literature reviews, it's clear that establishing integrated care is a multifaceted and long-term process, due also to the difficulties in showcasing the causality between the delivery of integrated care and outcomes.

There are many reasons for this. Firstly, in the context of integrated care it is not possible to effectively separate multicomponent strategies that are needed to achieve results. Secondly, the criteria for assessing the success of integrated care models are not necessarily specific or measurable. Lastly, there are few opportunities for making comparisons with alternative models or control cases. However, there does appear to be some guidance on the first steps required to make change happen; specifically, development of a common vision should be based on a clear articulation of the population's needs in local communities, which then can develop into a shared strategy for change. The identification of population needs, therefore, should be a starting point in developing any integrated care strategy. It is clear that even these first steps for integrated care require careful planning and that the process of change needs strong leadership and good management support

[7]. In other words, it's required a paradigm shift in policy action and a genuine commitment to engaging with communities in the attainment and protection of their health.

Since integrated care is strongly shaped by perspectives and expectations of various users in the health system, success of each solution is to depend on the context in which the integration is introduced, not just the initiative itself.

The conceptualization of integrated care is multidimensional and encompasses four key elements: a) the types of integration (e.g., functional, organisational, etc.); b) the breadth of integration (i.e., vertical or horizontal); c) the degree of integration; and d) the process of integration (i.e., structural, cultural, social) [2]. A recent review of the literature on integrated care revealed some 175 definitions and concepts [8]. The most common definition of integration comes from the World Health Organization: "The organization and management of health services so that people get the care they need, when they need it, in ways that are user friendly, achieve the desired results and provide value for money". This reinforces the fact that integration is a means to an end, not an end in itself.

WHO suggests a common set of principles, that provide a unifying values framework [6]. The core principles of people-centred and integrated health services are:

- Comprehensive – offering care that is comprehensive and tailored to the evolving health needs and aspirations of people and populations, with a commitment to universal health coverage.
- Equitable – providing care that is accessible and available to all.
- Sustainable – delivering care that is efficient, effective and contributes to sustainable development.
- Coordinated – ensuring that care is integrated around people's needs and effectively coordinated across different providers and settings.
- Continuous – providing care and services across the life course.
- Holistic – focusing on physical, socioeconomic, mental and emotional well-being.
- Preventive – tackling the social determinants of ill-health through action within and between sectors that promotes public health and health promotion.
- Empowering – supporting people to manage and take responsibility for their own health.
- Goal oriented – in terms of how people make health care decisions, assess outcomes and measure success.
- Respectful – of people's dignity, social circumstances and cultural sensitivities.
- Collaborative – supporting relationship-building, team-based working and collaborative practice across primary, secondary and tertiary care, and with other sectors.
- Co-produced – through active partnerships with people and communities at an individual, organizational and policy-level.
- Endowed with rights and responsibilities – that all people should expect, exercise and respect.
- Governed through shared accountability – of care providers to local people for the quality of care and health outcomes.
- Evidence-informed – so that policies and strategies are guided by the best available evidence and supported over time through the assessment of measurable objectives for improving quality and outcomes.
- Led by whole-systems thinking – that views the health system as a whole and tries to understand how its component parts interact with each other and how the system is influenced by factors beyond it.
- Ethical – by making sure that care optimizes the risk–benefit ratio in all interventions, respects the individual's right to make autonomous and informed decisions, safeguards privacy, protects the most vulnerable and ensures the fair distribution of resources.

Contextualizing integrating care to the field of rare diseases, it is important to underline that Rare diseases (RD) are heterogeneous in terms of prevalence, age of onset, clinical severity and outcome. However, they share various common features: they are often serious, chronic, progressive, degenerative and associated with co-morbidities. Rare diseases (RD) are heterogeneous in terms of prevalence, age of onset, clinical severity and outcome. However, they share various common features: they are often serious, chronic, progressive, degenerative and associated with co-morbidities. For most RD there isn't a specific treatment available and existing treatments are not always able to minimize all the complex impairments generated by the disease. Even when RD are not associated with a disability, will in many cases influence the person's health condition and impact on daily life in a disabling way [4].

To resolve this problem, some Member States are developing specific project to improve the knowledge and visibility of disabilities associated with RDs, and to provide tools to help the stakeholders. In France, for instance, Orphanet (the international database and portal on RDs and orphan drugs) is currently working on describing the functional consequences of each rare disease, having developed the Orphanet Functioning Thesaurus, derived and adapted from the International Classification of Functioning, Disability and Health – Children and Youth [9, 10]. According to surveys carried out by EURORDIS [4, 5]:

- 65% of respondents have to visit different health, social and local services in a short period of time;
- 67% feel that these services communicate badly between each other;
- 7 in 10 find that organising care is time-consuming and 6 in 10 find it hard to manage;
- 7 in 10 do not feel well informed about their rights;
- 7 in 10 reduce or stop their professional activity due to the disease and the care burden.

These everyday challenges result in significant loss of income and financial difficulties, often compounded by the need to relocate to another home adapted to their health needs or situated closer to the health or social services. Moreover, people living with a rare disease feel that they face discrimination in leisure activities (32%), education (30%) and daily activities (29%). 32% of patients also felt discriminated in the labour market, either when searching for a job (17%) or at their current job (15%) [11]. Then, in the particular context of rare diseases, including the challenges in regards to diagnosis, feelings of exclusion and lack of treatment generate a considerable moral suffering and burn out situations are frequent among patients and family members.

Hence it is clear that, although providing holistic support to any given patient is certainly an added challenge, the rare diseases are likely to benefit considerably from integrated care that bridges professions and knowledge bases. On the other hand, as early as 2008, the European Commission and Council recognized the need for coordination of care provided to people living with a rare disease, nationally and internationally, recommending Member States to [12, 13]:

- establish and implement plans or strategies for rare disease in order to aim to ensure that patients with rare diseases have access to high-quality care, within the framework of their health and social systems;
- organise healthcare pathways for people living with a rare disease through the establishment of cooperation with relevant experts, and exchange of professionals and expertise within the country or from abroad when necessary;
- encourage Centres of Expertise to be based on a multidisciplinary approach to care when addressing rare diseases;
- gather national expertise on rare diseases and support the pooling of that expertise with European counterparts in order to support: (a) the sharing of best practices on diagnostic tools and medical care as well as education and social care in the field of rare diseases.

EUROPLAN, the European Project for Rare Diseases National Plans Development (www.europlanproject.eu) played a crucial role in these activities. This project promotes a "double level" approach: respectful of national decisions but also intended to ensure a coherent and consistent progress in EU rare diseases care. In fact, trough EUROPLAN Recommendations [14] provided tools to Member States for developing a plan or strategy, linking it to a common framework at the European level. These recommendations and report of several national conferences [15] recommended taking into account the need for social inclusion, psychological and educational development for people living with rare, chronic and debilitating diseases. It's been also recognized the instrumental role of social services to the empowerment, the wellbeing and health of people living with a rare disease. Several adopted national plans include specific measures to facilitate coordination between health and social and support services. Various countries have already started to implement some of these approaches.

In 2016, the European Commission has reiterated and strengthened its position adopting "The Commission Expert Group Recommendations to Support the Incorporation of Rare Diseases into Social Services and Policies", and sustaining clearly the need to promote measures that facilitate multidisciplinary, holistic, continuous, person-centred and participative care provision to people living with rare diseases. In the holistic and person-centred approach, social services play a fundamental role to achieve a high level of social protection, health protection, gender equality, and economic, social and territorial cohesion. In fact, they should help people to participate fully in all aspects of life and to maintain own independence, in order to increase quality of life. To achieve these goals, social services should be closely interlinked with health services, educational services.

These documents, sided by other recent policy developments at European and national levels, represent an important policy step into approaching rare diseases' complex challenges in regards to holistic care provision [16].

Innovative approaches aiming at bridging the gap between health, social and community service and support providers are currently being developed and tested in different European countries: standards of care, networks of expertise, case management services, one-stop-shop services, amongst others.

The EU-funded project INNOVCare has also developed a factsheet with input from all stakeholders to highlight why integrated care is needed for rare diseases. This factsheet states that Integrated care ensures that people living with a rare disease and their carers:

- overcome the care burden that they face and secure the services and support that they require;
- achieve a quality of life on an equal footing with other citizens;
- participate in society and in the job market to their highest potential;
- fully realize their fundamental human rights.

The challenge of providing holistic care to people living with a rare disease is huge and requires multidisciplinary teams, involvement of all stakeholders as well as change of perspectives, of care provision concepts and of services. The organization of holistic care pathways at national level is essential to overcome this challenge. At national level, centers of expertise play an important role: are responsible for gathering and coordinating knowledge and care and – as such –- should promote the cooperation with other care providers, including social services and other local services. In France, 23 National Health Networks for Rare Diseases (Filière de Santé Maladies Rares) have been created by the Ministry of Health to coordinate actions between different stakeholders involved in care provision to people living with rare diseases. The mission of these Networks consists of reducing the diagnosis and therapeutic wavering; facilitating the entry and orientation in the care pathway; implementing actions in the social field (in collaboration with the National Solidarity Fund for Autonomy), targeted at improving social care and allocation of disability compensatory benefits. Specific actions are defined according to needs of the diseases covered by the network and inter-networks actions are also developed, for instance, a working group has been set up to improve education, pathway at school and care taking at school [16].

An excellent example of integrated care is also found in Resource Centres for Rare diseases, which have recently gathered in the European Network of Resource Centres – RareResourceNet. RareResourceNet aims at accelerating the development and the implementation of holistic high quality care pathways for people living with a rare disease across Europe, contributing to raise standards of care and support.

Resource centres for rare diseases are a one-stop shop service, complementary to health and social care services, specifically designed for people living with a rare disease and their carers. They provide holistic services and support, while also creating a bridge between patients and families and various stakeholders, services and professionals providing health care, social care, and social support – including rehabilitation, education and employment. They thus empower service providers, professionals, patients and carers to overcome the challenges of rare diseases. Moreover, they advocate for the adoption of holistic and integrated care services and policies in European countries.

An example of a resource centre for rare diseases is the NoRo Pilot Reference Center for Rare Diseases, in Romania, set up in 2011, through a project implemented in partnership with Frambu Norway (www.frambu.no) and funded by Norway Grants. This offers a social service and a medical service, which provides holistic care based on a multidisciplinary and complementary approach and on the individual assessment of patients' needs. The centre ensures continuity of care through a one-stop-shop style of service, specifically designed for people living with a rare disease, combining medical, social and educational service. The integration of social services through setting up one-stop-shop services has the potential to generate cost efficiency, effectiveness of the delivery and capacity to tackle complex and multiple problems while also ensuring take-up and coverage [17].

Another resource that is being promoted as guarantee of integrated care is the "case manager". To date, in most rare disease cases, the role of the case manager is assumed by patients or family members, without having sufficient information regarding care, the health and social system and relevant contacts. This situation is very burdensome for people living with a rare disease and their families. Family members – often the main carers – frequently find themselves in burn out situations, unable to cope physically and psychologically with the situation. Therefore, professional case managers are crucial in relieving the care burden faced by people living with a rare disease and their families.

These professionals represent an element that can ensure that there is a better coordination in the care pathway of people living with a rare disease, functioning as a link between the health and the social needs of the patient, particularly in very complex situations, due to the course of care and the need for the intervention of multiple structures and professionals. Case managers have an instrumental role in supporting patients and families as well as professionals.

The EU-funded INNOVCare project (www.innovcare.eu) has developed and outline for the role of case manager, with the input of all stakeholders involved in care delivery and decision making on care for people living with a rare disease [18]. According to this outline, case managers should:

- act as a single and stable point of contact;
- listen, inform, support and empower patients and families;
- asses and monitor patients' and families' needs;
- provide holistic, patient-centred care planning & care co-ordination;
- act as a hub of information and knowledge;
- inform, support and empower care professionals;
- facilitate coordination between services/networks of services;
- help to prevent risks and to limit use of health services, when these may not be needed;
- develop working methods that support patient/families empowerment.

The INNOVCare project is also the testing use of case managers in the context of rare diseases, and should bring to light more information on the impact of this type of service on care provision and on the quality of life of patients and families. Main goal of this project is collect data on unmet social needs of people living with a rare disease and their families in the EU, analyse existing social care pathways in a selection of Member States in order to facilitate the creation of a European network of resource centres to ensure exchange of good practices.

Another example can be found in The Netherlands, where case management for an individual with a rare disease is often divided into organisational and medical components. For help regarding the organisational aspects of care as such, the "case manager" is a nurse-practitioner who is in close contact with the responsible clinician. For medical issues only, there is the so-called physician-manager, who coordinates the multidisciplinary care and is the immediate contact for medical questions. This physician, having a broad overview of the disease and its health and psychosocial impact, can refer the patient to other professional care-givers within the network of expertise or outside of it for paramedical care or other types of services [16].

Lastly, European Reference Networks (ERNs) and their constituent healthcare providers are also key actors in facilitating integrated care for rare diseases, in accordance with recommendations adopted by EUCERD and by the Commission Expert Group on Rare Diseases. ERNs can support integrated care by for example follow a multi-disciplinary approach and functioning as a platform to share experiences and good practice. Centres of expertise, on their hand, can coordinate within the specialised healthcare sector multidisciplinary competences/skills, including paramedical skills and social services. They also can provide education and training to non-healthcare professionals (such as school teachers, personal/homecare facilitators) as well as contribute to and provide accessible information adapted to the specific needs of patients and their families, of health and social professionals. Discussions on the roles of ERNs in supporting integrated care can also be found in the report of the Joint RD-Action and INNOVCare workshop on "Creating a Sustainable Environment for Holistic & Innovative Care for Rare Diseases & Complex Conditions" (April 2018). This workshop also highlights several other important topics, case studies and good practices on integrated and holistic care for rare diseases, which are available for download online on the project website.

CONCLUSIONS

Various methods are currently being used to promote integrated care for rare diseases and there are yet several challenges to fully address this issue. However a review of experiences in implementing integrated care in Europe has identified elements of good practices deemed to be successful and which potentially could be transferable across Europe. Were identified several inter-related "building blocks" or "system levers" for the effective design and implementation of integrated care frameworks [19, 20]. These relate to:

1. Political support and commitment. System-wide transformative change can only happen when many policy levers are aligned and activated towards shared goals.
2. Governance. Establishing strong governance mechanisms at both national and local level and among all service providers, care authorities and actors involved is an essential step in configuring integrated care models.
3. Stakeholder engagement. The broader the ambition, the more numerous and diverse are the stakeholders that should be engaged; effective communication strategies establish trust, confidence and good collaboration and involvement of all stakeholders.
4. Organisational change. The provision of integrated care and service redesign implies changes in the healthcare structures, organisation of workflows, workforce development and resource allocation to provide more responsive care delivery.
5. Leadership. Effective national leadership and the emergence of local leaders are important factors in managing the complex process of transformation and implementation of integrated care solutions.
6. Collaboration and trust. The broad set of changes needed to deliver integrated care presents a significant challenge that can be partially overcame by the willingness to collaborate and put the interest of the overall care system above individual incentives.
7. Workforce education and training. The implementation of integrated care solutions often requires the redesign of health and social care professionals' roles and the creation of new roles to ensure continuity of care.
8. Patient focus/empowerment. The patient is a member of the "care team": he or she must be involved in the decision-making processes, and care plans need to be tailored to patients' individual needs.
9. Financing and incentives. Different funding models can support the transition to the time when the new integrated services are fully operational and the older ones are decommissioned.
10. ICT infrastructure and solutions. Integrated care requires the sharing of health information across diverse providers to enable continuous collaboration and citizens' active involvement.
11. Monitoring/evaluation system. The establishment of monitoring and performance evaluation systems is essential to provide evidence of the impact on quality of care, cost of care, access and citizen experience.

To date, the evidence base for the benefits of integrated care on both patient outcomes and cost effectiveness is based yet on small-scale examples, although the scale of implementation is slowly growing. Better, more comparable and longer term data collection and reporting will be crucial for building a more comprehensive evidence base.

Promoting integrated care and bridging the gaps between health and social care for rare diseases is not only necessary but crucial to increase the life expectancy, quality of life and autonomy of people. For this reason, to guide future policies integrated assistance, it's recommended that:

- information on ongoing pilot projects/case studies and good practices is consolidated and widely disseminated: the long term impact assessment of the pilot care provisions is essential to support robust evidence based decision making on integrated care, as the impact on quality of life and the return on investment are hardly short term outcomes; research on economic evaluation of the integrated care, should consider the economic long term impact beyond the healthcare and service provision onto a society level: taking into account the consequences of the impact of integrated care provision on patients' and carers' health, wellbeing, autonomy and financial burden [16];
- the evaluation of impact uses a suitable comprehensive set of outcome indicators that take into account both the evaluation of impact of healthcare and social services' interventions as well as the personal quality of life outcomes for patients, their families and carers;
- patients and families are directly engaged in the design and implementation of these innovative solutions.

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