Ann Ist Super Sanità 2019 | Vol. 55, No. 3: 292-295
DOI: 10.4415/ANN_19_03_16



# Resilience in rare disease networks

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**Abstract**
A resilient system is one which continues to perform its function or goal during a period of change. The original concept was formed around return to the *status quo* after major external shocks. Recently the concept of "everyday resilience" has been proposed. Everyday resilience is the adaptive and learning response of systems to the daily disturbance of normal routines. For everyday resilience, human factors are as important as physical resources. Rare disease networks can use several strategies to build resilience.

**Key words**
- resilience
- networks
- rare disease

## INTRODUCTION

A system or network may respond to change in three ways – absorb, adapt or transform.

For example, if a team member is off sick, the extra workload may be absorbed by colleagues who see more patients or work longer hours. In a network, the network as a whole may absorb change in the same way: if a key member of staff at one centre is absent, the work (for example, laboratory specimens) could be sent other centres in the network.

If the change cannot be absorbed, it may be possible to adapt to the change. For example a rare disease centre which faces a shortage of medical staff may adapt by changing its skill mix to increase the use of specialist nurses with extra qualifications.

The third possibility is to transform the organisation, system or network. Large scale transformation rarely happens because it is so difficult to do well. But for example a network based on seeing patients face to face may transform to a model of telemedicine; or a treatment network may transform to a teaching network to expand its depth and coverage. More fundamentally a medical network centred on hospitals may transform to a patient-based network while maintaining its goal of improving quality of life for people with rare disease.

The development of European Reference Networks has raised the question of the long-term sustainability in networks. One aspect of this problem is resilience, traditionally understood as the ability of a system to function during, and return to normal after, an external shock. This paper aimed to explore current thinking on network resilience in healthcare.

## METHOD

The bibliographic databases Medline and Embase were searched on 13 December 2017 using the terms "resilience" or "resilient" or "resiliency" and "network" or "system" and "health" or "healthcare". Abstracts were scrutinised for relevance and full-text papers retrieved. A narrative review was conducted.

## RESULTS

After de-duplication, 347 citations were retrieved. A great majority of these papers focussed on psychological resilience in individuals not resilience in networks. After scrutiny of abstracts, 12 papers were retrieved for full text reading and narrative review.

## DISCUSSION

### *Resilience and surge capacity*

The original concept of resilience was developed as the response to massive external change. Classic examples include physical disruption (earthquake, flood, or terrorist action) or events such as SARS or Ebola. Massive economic shocks may have the same effect on health systems.

Therrien *et al.* [1] discuss the relationship between surge capacity and resilience. They describe four aspects of surge capacity, known as the 4 'S':
- staff;
- stuff (e.g. supplies and equipment);
- structures (e.g. hospitals);
- systems (e.g. processes for decision making).

A resilient system will have accessibility, diversity and redundancy in the first three categories, but also "appropriate models of decision making, communication and sense making, supported by organizational values such as self criticism, respect among employees, innovation, a sense of responsibility, and the application of rules and best practices".

Therrien *et al.* [1] use their analysis of the H1N1 epidemic in Canada to suggest three dimensions for planners to consider. These three dimensions are related to the types of complexity (detailed and dynamic complexity), the temporal aspects of resilience (passive and proactive resilience) and the nature of order (favorable order and favorable disorder).

This framework specifically relates to resilience in crisis situations where surge capacity is required. The underlying goal is returning the system to its state before the external shock. The next section considers the recently developed concept of "everyday resilience".

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### *Everyday resilience*

Resilience has traditionally been conceived as the response to the massive disruption of major events such as H1N1 or major economic crisis. Recent work has developed the concept of "everyday resilience". Barasa *et al.* [2] provide a theoretical framework and Gilson *et al.* [3] give case studies from Kenya and South Africa.

Barasa *et al.* [2] challenge the simple concept that resilient systems return to their original state after an external shock. This implies that systems are linear and static. But in fact health systems are constantly changing, in a myriad of small ways. They are adaptive complex systems. These systems consist, in Barasa's typology, of both "hardware" (infrastructure, commodities, human resources, finance) and "software". The software is both tangible (management knowledge and skills, and organizational systems and procedures) and intangible (software of values and norms, relationships and power). Barasa *et. al* feel that it is the software which promotes resilience. Thus "resilience becomes an active process within a dynamic health system that is constantly navigating challenges by becoming better".

The case studies of Gilson *et al.* [3] illustrate these concepts. They studied a district in Kenya and two health districts in South Africa. Three common sets of issues were identified:

- unstable and evolving governance structures;
- resource challenges and frequent policy change;
- instability at the service delivery front line.

Gilson et al comment that "challenging conditions that are the norm for those working in district health systems in low-income and middle-income countries. Health managers at these levels routinely face instability, such as changes in governance structures and financing mechanisms, payment and other resource provision delays, and frequent, abruptly imposed policy directives. They commonly work with unstable authority delegations, manage unpredictable staff and address changing patient and community expectations. These conditions are not the acute, external shocks more usually discussed in relation to health system resilience" [3].

This case study focused on the role of managers in a hierarchical system, with sub-district, district and national levels. Rare disease networks such as the European Reference Networks have different governance structures and no clear managerial hierarchy. Nevertheless, many health systems could agree that "challenging conditions are the norm".

### *Network resilience*

There are very few published studies which examine resilience of networks (as opposed to individual hospitals).

Sheaff *et al.* [4] provide case studies of four networks in the English National Health Service at a time or organisational change. They define network "macroculture" as the complex of artefacts, espoused values and unarticulated assumptions through which network members coordinate network activities. These components of artefact, value and assumption are further explained as follows:

*1. Artefacts are of two kinds*

a) the network's collective products or services – its "core artefacts" – and the technologies and inputs used to produce them;

b) symbolic artefacts which physically represent (e.g., as logos, publications) the values described below.

*2. Values, which are also of two kinds*

a) espoused, negotiable values concerning: what issues, problems and tasks face the network; network members' roles; rules of conduct; conventions (accepted approaches and solutions to problems); and specialised language;

b) taken-for-granted, non-negotiable values: basic underlying assumptions, often so internalised as hardly to be consciously formulated, for instance defining the "moral economy" governing members' behaviour.

Examples of artefacts from a network for coronary heart disease included:

- a new sub-regional primary angioplasty service;
- ensuring more equitable care for patients at the interface between secondary and tertiary care;
- adaptation of national standards, e.g. [national] guidelines, to the local situation;
- increasing uptake of cardiac rehabilitation.

Sheaff *et al.* found that artefacts adapt to change faster than values, and values adapt faster than assumptions [4].

For a Europe-wide rare disease network, it seems likely that core artefacts will be products such as guidelines or consensus conferences. The espoused values are likely to be set out in the constitution or governance documents of the network; and we may speculate that the basic underlying assumptions about behaviour and so on may come from a common socialization into the profession of medicine and its allied disciplines. But cultural differences between countries – for example assumptions about how politeness is enacted or gratitude is expressed – may affect the function of multinational networks.

### *Mathematical models*

Mathematical models of networks, though often hard to understand for non-specialists, may suggest features of networks worth exploring in the real world.

Gao et al. [5] built a mathematical model of "complex" networks, characterised as "systems are composed of numerous components linked via a complex set of weighted, often directed, interactions". This model predicted that density, heterogeneity and symmetry are the three key structural factors affecting a system's resilience.

It is not clear how well this model describes current rare disease networks. We do not yet have descriptions of properties such as density, heterogeneity and symmetry. The requirement for European Reference Networks to have members in at least eight member states guarantees some level of heterogeneity because of the different health systems in which the centres are located. Symmetry implies that the networks should take care not to be dominated by one or two large centres. Density may come from an active network with plenty of interactions between all members of the network (as opposed to pairs or cliques which ignore the full membership).

### *Human factors*

Martineau [6] describes "people centred health systems" in a commentary on the Ebola crisis in West Africa. He calls for a focus on the people, relationships and local contexts that constitute health systems and the practices that produce crisis responses. He comments [6] as follows:

"Recognising that flexibility, for example, is important in how a health system responds to a major crisis must be complemented by understanding how people within a particular health system might actually become more flexible in their roles or actions, or its knock-on effects on other important health system properties. The capacities of health workers to reprioritise their clinical activities, of people who are unwell to alter their care-seeking practices, or of previously non-health actors to take on new health roles vary hugely between and within health systems, and depend in particular on power and trust relationships between each actor".

This focus on people, on social dynamics and on the building of relationships reminds us that rare disease networks are not an abstract entity. They are a gathering of people – a community. Attention must be paid to the building of that community through normal social interaction. Martineau states that "system strengthening initiatives must embed explicit localized efforts to build mutual trust, respect and dignity between health actors and the communities they serve alongside initiatives to improve the clinical quality of care". Seen in this light, opportunities to meet face to face are important. Also events such as conference dinners are not optional extras but part of the process.

Olafsdottir *et al.* [7] provide an example of the need to involve communities. The 2008 economic crisis in Iceland developed over a matter of days, requiring severe cutbacks in public sector spend in all areas. In the health sector, the immediate response included closing down units (resulting in staff redundancies), changing 7-day wards to 5-day wards, and reducing overtime payments. For the first time in the history of Iceland, out-of-pocket payments for hospitalisation were introduced, which allowed for charges every time people had to be hospitalised, except in case of births.

Three months after the crisis the Minister, who had relied heavily on external consultants, announced further proposals [7]:

"[One proposal] was to convert one of the hospitals in the capital area into a geriatric institution. Services usually offered in this hospital were to be redistributed to other hospitals. Some of the specialised services were to be moved to the main hospital in the capital, others to be tendered out to the private sector. The operating theatres, however, were to be merged with the operating theatre in a hospital outside the capital area (Sudurnes), where they were to be run as a new private entity led by health professionals".

These proposals were however not adopted because of a change of government in February 2009 and the resultant change in political philosophy.

Olafsdottir *et al.* consider that the response to the economic crisis was weak because of poor transparency (documents and analyses supporting decisions were not made public) and poor opportunities for participation by all stakeholders (over-reliance on external consultants) [7].

### *Evaluating and building resilience – Resilience Index*

Kruk *et al.* have proposed a Resilience Index [8]. Although designed for national health systems, it is easily adaptable to networks. Five "characteristics" are proposed: aware, diverse, self regulating, integrated, adaptive. Aims and measures are set out for each characteristic, with a total of 25 measures for systems to consider. For example a self regulating system will aim to isolate threat and maintain core functions, and to leverage outside capacity. The measures for this are memorandums of understanding with non-state providers and a database of service delivery alternatives for affected and non-affected populations; and collaboration agreements with regional and global actors.

In the field of rare disease, for example, production problems have created drug shortages which required engagement with regional and global actors such as European patient organisations and global pharma companies. More locally problems in the home care supplier markets have led to a requirement for databases of service delivery alternatives.

Thomas *et al.* [9] offer a simpler framework with a stronger emphasis on financial and economic aspects: this framework was from a case study of health systems in Ireland following the 2008 economic crisis. They propose three categories, and some measures for each, as follows:

- financial resilience (e.g. Protection of health funding compared to economic decline);
- adaptive resilience (e.g. Reduction in staffing with no commensurate reduction in service, Protection of services – no loss of entitlements or rationing by volume);
- transformatory resilience (e.g. Clear specification of reforms, Evidence base for reforms).

## CONCLUSIONS

Rare disease networks should build everyday resilience by consciously developing their day-to-day interactions. They should also examine their macroculture of artefacts, espoused values and unarticulated assumptions through which network members coordinate network activities. Mathematical models suggest the importance of density, symmetry and heterogeneity but it is important to remember the people-centred aspects of networks.

Networks can assess their resilience by using a Resilience Index.

### *Acknowledgements*

I am grateful to Maurella Della Seta and her team for literature search and library help.

### *Funding*

This work was supported by the Health Programme of European Union, in the framework of the Joint Action for Rare Diseases, Project n. 677024 "Promoting

Implementation of Recommendations on Policy, Information and Data for Rare Diseases – RD-ACTION".

***Conflict of interest statement***

The author declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Submitted on invitation.
*Accepted* on 24 April 2019.

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