

# How to capture the individual and societal impacts of syndemics: the lived experience of COVID-19

Stefan Boes,<sup>1,2</sup> Carla Sabariego,<sup>2,3</sup> Jerome Bickenbach,<sup>2,3</sup> Gerold Stucki<sup>2,3</sup>

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## BACKGROUND

To capture the complex interactions between health and social crises that he noticed in the HIV-AIDS pandemic, medical anthropologist Merrill Singer in the early 1990s invented the term *syndemic* to describe the ‘closely intertwined and mutual enhancing health problems that significantly affect the overall health status of a population’.<sup>1</sup> Singer and Clair later expanded the notion to reconceptualise disease in a biosocial context,<sup>2</sup> making the link to a *systems approach to public health*.<sup>3</sup> Diseases, and especially highly infectious diseases that lead to pandemics, are never isolated assaults on the health of populations: they occur within a broader context characterised both by epidemiological patterns of other diseases and by social and economic factors that can dramatically affect transmission. Diseases themselves interact, creating disease clusters, and social and economic factors that affect disease dynamics are affected by them in turn. Conditions of social inequality—poverty, stigmatisation, stress and violence—play a role in disease exposure, and may dramatically increase vulnerability. Over the course of a pandemic, these same social conditions may also worsen. The value of syndemic thinking is that it ‘brings together the environment and individual embodied experience to think about what types of interventions matter—from social policy to clinical practice’.<sup>4</sup> In 2019, *Lancet* commissioned a report on the global syndemic of obesity that highlighted the ‘multilayered and multidimensional array of factors implicated in the dramatic global rise of obesity, undernutrition and climate change’.<sup>5</sup>

It should come as no surprise that we are now invited to view COVID-19 not as a pandemic but a syndemic.<sup>6</sup> The characterisation fits what we know of the disease since both its spread and its lethality are strongly shaped by the impact of comorbid chronic health

## Summary box

- ▶ The notion of a ‘syndemic’ has recently been suggested as an apt description of the COVID-19 pandemic.
- ▶ A syndemic approach requires suitable causal models for disease interaction within the broader social and economic context, which poses a challenge for data collection.
- ▶ The WHO’s International Classification of Functioning, Disability and Health (ICF) is both a conceptual model for interactive relationships and a classification.
- ▶ The ICF provides an interaction model that can contribute to fulfilling the promise of a truly syndemic understanding of COVID-19.

problems, especially the non-communicable diseases of hypertension, obesity, diabetes, cardiovascular and chronic respiratory diseases, and cancers.<sup>7</sup> There is also evidence that COVID-19 has a greater impact on social groups that experience greater social and economic inequality.<sup>8</sup> Confirming the underlying hypothesis of syndemic theory, COVID-19 infection and mortality patterns have been shown to differ across countries and regions, and early evidence suggests that they depend at least to some extent on the social, political and economic context. In the USA, the Centers for Disease Control and Prevention researchers have shown differences in infection and mortality by racial and ethnic background,<sup>9 10</sup> and a recent study more broadly indicates that infection and mortality patterns reflect income inequality and its social consequences.<sup>11</sup> Others have argued that the reverse may also be true: the spread of the disease and its economic impact will further worsen the inequalities in the USA and around the globe.<sup>12 13</sup>

Some have questioned not the syndemic framework itself, but the appropriate level of its application in the case of COVID-19. Emily Mendenhall,<sup>14</sup> for example, argues



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<sup>1</sup>Department of Health Sciences and Medicine, University of Lucerne, Lucerne, Switzerland

<sup>2</sup>Center for Rehabilitation in Global Health Systems, WHO Collaborating Center, University of Lucerne, Lucerne, Switzerland

<sup>3</sup>Swiss Paraplegic Research, Nottwil, Switzerland

## Correspondence to

Professor Gerold Stucki; gerold.stucki@paraplegie.ch

persuasively that COVID-19 cannot be said to be a global syndemic because both the biological, but more importantly, the social and political drivers of the spread of the disease differ substantially between countries, and even between regions of countries. While there is a syndemic in the USA—because of its political failures to address racial and other disparities—it may not be correct to say there is a syndemic in, say, New Zealand where social factors are very different and less impactful on the spread of the disease. Whether the syndemic approach can only be applied locally has potential methodological consequences, as we shall see, but the general question of the value of the syndemic approach to understand COVID-19 as a global threat remains, as Mendenhall readily acknowledges.

Yet, even if calls for viewing COVID-19 as a syndemic may be well founded, the consequences for public health and clinical practice are not always clear. The claim that ‘addressing COVID-19 means addressing hypertension, obesity, diabetes, cardiovascular and chronic respiratory diseases, and cancer’<sup>6</sup> is undoubtedly true but not very helpful in a social environment where public health measures, such as time-constrained lockdowns, have been politicised and made controversial. Potentially more useful is to pursue the insight that syndemics require a ‘systems-thinking’ approach, and that it is both naïve, and ineffective, to reduce the social response to COVID-19 to the simple narrative of personal protective measures (PPM) (including the use of protective masks and physical distancing) and vaccination towards herd immunity, while ignoring the ‘context of the human host, its immune system, microbiome and economic, social and natural environment’.<sup>15</sup> No doubt it is essential to appreciate the complexity of interacting factors in the prevention and response to COVID-19, as it is to recognise that society is a complex system that resists simplistic causal explanations.<sup>16</sup> Yet even staunch proponents of the syndemic approach point to its Achilles’ heel—the fact that ‘the theory of syndemics has received scant empirical support either for its concept of disease interaction or for the model of mutually causal epidemics...[illustrating] important methodological gaps in the literature’.<sup>17</sup>

If finding suitable causal models for disease interaction—especially between communicable and non-communicable diseases—is a methodological challenge, adding the broader societal context increases this challenge exponentially. Inasmuch as societies in general and health systems in particular are complex adaptive systems,<sup>18</sup> it is inevitable that a ‘systems-thinking’ approach will be required to operationalise the full consequences of syndemic insights, even if these are applied only in local situations. Any approach to realising the aspirations of the syndemic approach, in short, needs to be comprehensive, at least at the outset.

To begin with, it is important to be clear what the individual and societal impacts of COVID-19 are. Individually and socially, the most important impact is on mortality, which in the case of COVID-19 has reached 3.5 million

global deaths at the time of writing.<sup>19</sup> Disease morbidity, and its consequences, impacts both individuals and society. In addition, after the infection has been controlled there is increasing evidence of ‘COVID-19 long hauling’ (also referred to as post COVID-19 condition) characterised by a postrecovery persistence of ‘rolling waves of symptoms’ including fatigue, hallucinations, ‘brain fog’, delirium, memory loss, tachycardia, numbness and tingling, and shortness of breath.<sup>20</sup>

Through a syndemic lens, however, we need also to take into account the impact of the social response to the disease. A syndemic is thoroughly interactive, and both directions need equal attention. Countries worldwide have instituted basic public health measures such as masking, hygiene and distancing rules; others have gone further to put into effect far-reaching measures, such as travel restrictions, business and school closures, extended lockdowns, quarantines and curfews. High-resource countries are vaccinating at unprecedented rates (approaching 1.8 billion doses administered at the time of writing),<sup>19</sup> although the pace for medium and low-resource countries is much slower and greatly depends on the capacity of wealthier countries to share their stocks of the vaccine. All of these measures aim to contain the spread of the virus, protect the most vulnerable groups of the population and prevent the collapse of healthcare facilities in light of overwhelming case numbers. Yet at the same time, many of the public health measures, and lockdowns and closures in particular, have had significant negative effects on societies and economies due to lost production and lower value added in affected business sectors, higher rates of unemployment, learning deficits and lost education, and physical and mental health consequences indirectly related to COVID-19, again with very different impacts depending on the social and economic context.

Taking all the synergetic impacts that constitute a syndemic into account—both as a matter of the lived experience of individuals, infected or indirectly affected by COVID-19, and the direct and indirect social and economic consequences of the disease—will require complex and interactive research frameworks and conceptual models, both quantitative and qualitative, and the systematic collection of reliable information. If we take the bold step of fully applying the syndemic approach, traditional epidemiological data and information on basic socioeconomic indicators may not be sufficient to comprehend the full extent of the impact of COVID-19. As Mendenhall and Singer have argued,<sup>14</sup> the syndemic approach, initially shaped by ethnography, should continue to rely on nuanced anthropological and other qualitative methodologies. But what is particularly required is a broadly based, interdisciplinary and truly interactive conceptualisation of the individual experience of health and the societal response to the needs created by that experience.

The objective of this paper is to suggest that an appropriate conceptual model to guide the collection of

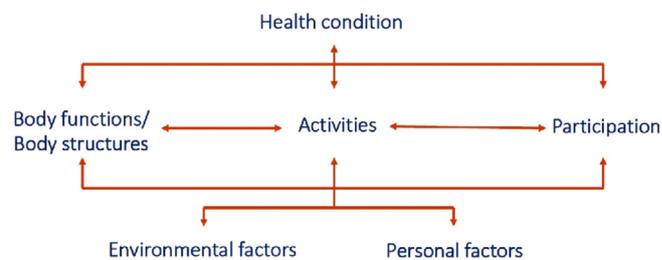
relevant information capturing the syndemic interactions and resulting societal response is the WHO's *International Classification of Functioning, Disability and Health* (ICF).<sup>21</sup> The ICF, we argue, can serve as an overall conceptual model for data collection that can be used as a reference framework for both quantitative and qualitative data collection efforts and is compatible with a wide range of data collection methodologies. Based on the interactive model of functioning, the ICF can serve as a reference framework for augmenting existing data in order to fully capture the extent and dimensions of the individual and societal impacts of COVID-19, and other syndemics. Moreover, as a classification, the ICF provides an international reporting system for syndemic information from whatever source.

### THE ICF AND THE SOCIAL IMPACT OF SYNDEMICS

Although it was developed for several applications and use cases, and has since its endorsement by the World Health Assembly in 2001 been used for many purposes, the primary aim of the ICF was to augment WHO's International Classification of Diseases (ICD) to more fully capture information about health and the lived experience of health.<sup>22</sup> In effect, WHO created, alongside mortality and morbidity, the third health indicator of 'functioning', expressly to capture the impact of an underlying health problem on the life of individuals in the actual context in which the individual lives, acts and participates in all areas of interpersonal and social life.<sup>23</sup> The ICF, although primarily a classification, implicitly models the dimension of functioning as an outcome of multidimensional interactions between the intrinsic health state of a person and his or her actual physical, human-built, interpersonal, attitudinal, social, economic and political environment. Functioning, in short, is the lived experience of health, and problems in functioning or disability are what matter to people about their health state as they carry out their lives.<sup>24</sup>

COVID-19 is an infectious disease with widespread symptoms, sequelae and lethality, information about which is captured in the first instance by mortality and morbidity. Nonetheless, functioning information is required to better understand the impact of the virus on people's lives, during and after the infection, in case of persistent symptoms, and especially the impact of social, political and attitudinal determinants on the functioning of individuals in their daily lives. Taking full account of context, two persons with similar COVID-19 symptoms can have very different levels of functioning in their daily lives due to specificities of the physical, interpersonal, social and political environments in which they live.

The ICF offers both an interactive model and a reference classification to describe the full impact of COVID-19 on life, at the individual or population level, taking into account the environmental context in which persons live—from living conditions and personal relationships to social and economic factors. The underlying



**Figure 1** Graphical illustration of the conceptual model of WHO's International Classification of Functioning, Disability and Health (ICF).

conceptual model of the ICF (see figure 1) brings together the salient components of interactive process that creates both the individual's experience of health and the societal impact. The capacity of the ICF to fully describe the health state of an individual or a population, and the full context in which the person or population with specific health states live and act, as well as the interactions between individuals and the wider social context, makes it possible to capture the lived experience of a health condition such as COVID-19. Indeed, the ICF provides us with the syndemic picture of the disease from the individual perspective, used either in clinical routine or, from a population perspective, in health surveys, providing the foundation for data collection tools for both perspectives (see also table 1). The result is a kind of syndemic social lens through which the complex interactions that shape the trajectory of COVID-19 can be described and ultimately explained.

### COVID-19 AND HEALTH INDICATORS

Mortality and infection rates of COVID-19 are statistics that rely on the standardised reporting of cases made possible by a common reference system of WHO's ICD. What is not reported so far in a standardised manner is how both those with infections and those who have recovered from the infection are functioning in their daily lives. We lack an enormous amount of information at the moment, information that will be needed to plan the medium-term and long-term responses of health systems to COVID-19, or possible future variants, including, for instance, the need of rehabilitation for full recovery.<sup>25</sup>

ICF is a conceptual model and classification framework for identifying and recording evidence on the lived experience of individuals from an interactive perspective, that is, fully taking into account the role played by their social, economic and political environments. The usefulness of ICF has been demonstrated especially in the context of rehabilitation. In order to better understand COVID-19, and to support full recoveries, we need to foster the identification and collection of functioning data—both clinical and environmental—as has been recently proposed by the International Society of Physical and Rehabilitation Medicine (ISPRM): using the ICF-based Clinical Functioning Information Tool (ClinFIT), a tool for health professionals who provide rehabilitation, as a starting

**Table 1** Overview of the Clinical Functioning Information Tool (ClinFIT) and the WHO and World Bank Model Disability Survey (MDS), both exemplary ICF-based instruments

Instrument	ClinFIT COVID-19	MDS
Developers	International Society of Physical and Rehabilitation Medicine	World Bank and WHO
Type of instrument	Clinical tool for health professionals	Household survey (long version) and module for integration in existing household surveys (brief version)
Target population	Patients in acute, postacute and long-term settings	General population
Type of data	Health professional rating	Self-report data obtained through interview by trained interviewers
Functioning	The acute version collects data about energy and drive, sleep functions, attention functions, emotional functions, pain, respiratory and respiratory muscle functions, exercise tolerance functions, mobility of joint functions, muscle power functions, carrying out daily routine, handling stress and walking. The postacute version additionally covers moving around and structure of the respiratory system while the long-term version additionally covers moving around, remunerative employment, structure of the respiratory system, and recreation and leisure.	The long version includes 47 questions covering the extent of problems in mobility, hand and arm use, self-care, seeing, hearing, pain, sleep and energy, breathing, affect, interpersonal relationships, handling stress, communication, cognition, household tasks, community participation, caring for others, and work and schooling. The brief version covers the extent of problems in mobility, self-care, sleep and energy, handling stress, cognition, household tasks and community participation.
Environmental factors	No information is collected.	Broad inventory of questions about: <ul style="list-style-type: none"> <li>▶ Hindering or facilitating aspects of the general environment.</li> <li>▶ Use and need for personal assistance.</li> <li>▶ Family and social support.</li> <li>▶ Attitudes of others.</li> <li>▶ Accessibility to information.</li> <li>▶ Regular use of medication.</li> <li>▶ Use and need for assistive products for self-care, mobility, cognition, seeing and hearing.</li> <li>▶ Presence and need of modifications at home, school, work and community.</li> </ul>
Conceptual framework	International Classification of Functioning, Disability and Health	International Classification of Functioning, Disability and Health

ICF, International Classification of Functioning, Disability and Health.

point, ISPRM developed a version suitable to capture the functioning of patients with COVID-19 during and after the infection.<sup>26</sup>

Given that so little was known about the pathogenesis and epidemiology of COVID-19 when early cases were reported out of China, it was reasonable that the social response was focused on short-term public health measures. Soon enough, however, the uncontrolled spread of this highly infectious disease was far reaching and very different from that of a non-communicable disease.<sup>27</sup> In particular, we soon saw the need to take into account the middle-term and long-term social impacts of post COVID-19 condition as well as the impact of non-pharmaceutical interventions (NPIs) that societies have instituted in order to limit the spread of the disease. Applying the syndemic model, moreover, requires a comprehensive analysis of disease dynamics and social dynamics. In order to understand the complex interactions, both between COVID-19 and other health conditions and the social and economic responses to and impacts of the disease, and to better prepare countries and health systems for future challenges, we need to ensure that we collect data, at the population level, that fully capture all aspects of the syndemic model of the

disease. Here, too, WHO's ICF is a useful framework: ICF models individual and population outcomes in terms of interactions between health states and social, cultural, economic and environmental factors and has served as basis for a full range of population surveys, such as the WHO and the World Bank Model Disability Survey (MDS).<sup>28 29</sup> In short, ICF can both support systematic data collection and reporting and guide the social response to COVID-19 that takes into account the bidirectional disease social impacts.

The issue of what to measure in the case of COVID-19 would ideally be a core set developed for COVID-19, in the pattern of existing core sets for ankylosing spondylitis, breast cancer and stroke.<sup>30</sup> However, in light of the urgency of the current pandemic, the ClinFIT COVID-19 tool, which can be used in acute, postacute and long-term settings and whose development followed a multi-step process including a survey of ISPRM members worldwide, is the best starting point in terms of what to measure.<sup>31</sup> Given the clinical character of ClinFIT COVID-19, it collects only essential information on *body functions* (energy and drive functions, sleep functions, attention functions, emotional functions, pain, respiratory functions, respiratory muscle functions, exercise

tolerance functions, mobility of joint functions, muscle power functions), *body structures* (structure of the respiratory system) and on *activities and participation* domains (carrying out daily routine, handling stress and other psychological demands, walking, moving around, remunerative employment, recreation and leisure).

At the population level, a comprehensive ICF-based survey like the WHO and the World Bank MDS is suitable for generating an overall score of functioning with metrical properties, an indicator that can complement mortality and morbidity indicators by proving a measure of how COVID-19 impacts the functioning and health of individuals. Moreover, the MDS can support the identification of key social and economic determinants of the functioning of persons with or without COVID-19<sup>29</sup> and the impact on the spread of the disease itself across the population. The MDS—the current standard recommended by WHO to assess functioning at population level—is a dedicated survey available online in two formats: a stand-alone comprehensive survey, including a large inventory of environmental factors, and a brief functioning module (brief MDS) for inclusion in household surveys.<sup>28</sup> Since the brief MDS is concise and generates good overall scores of functioning,<sup>29</sup> it might be a good choice for assessing functioning in the context of COVID-19 in the scope of routine household surveys.

Table 1 provides an overview of the ClinFIT COVID-19 tool and the MDS. However, we suggest broadening the scope of functioning surveys like the MDS to be more sensitive to the COVID-19 syndemic, especially regarding the role of social determinants and other environmental factors. For instance, it will be useful to include domains that capture access to PPMs, and to target more detailed information on, for instance, socioeconomic status, access to financial benefits and financial stability of households.<sup>32</sup> This would account for the full consequences of NPIs, such as the impacts on employment and structural changes in the economy, lowering production, income and consumption.<sup>33–36</sup> Other domains would detail specifics of the natural environment and community and civic life. Each domain considered needs to be evaluated in terms of both positive and negative socioeconomic impacts. For example, the imposed NPIs across countries might reduce air pollution due to the reduction of air travel, mobility and land transport,<sup>37</sup> while at the same time less available income may increase the use of cheaper, less environmental friendly products, and fewer public resources may slow down investment in research and environmental protection.<sup>38</sup> There are also concerns that strict NPIs such as curfews lead to increased domestic violence,<sup>39</sup> although other types of crime may be less prevalent.

In order to include such macrolevel information into ICF-based surveys sensitive to the evaluation of a syndemic, the adaptation of indicators, such as those used by the Organisation for Economic Co-operation and Development<sup>40</sup> or the World Bank,<sup>41</sup> to self-report is appropriate. To allow for an evaluation of NPIs, standards such as

the Oxford COVID-19 Government Response Tracker should be used from the perspective of the person.<sup>42</sup> This stringency index should be complemented with information on the impact of government actions aiming to strengthen the economy, such as income support and debt relief for households, or other fiscal measures, as described, for example, by the International Monetary Fund or the International Labour Organization, on the survey respondent.

It is important to stress, however, that a fuller picture of a syndemic can only be created by more nuanced qualitative data from ethnographic, historical and other approaches. These can capture particular features of individual and social interactions, which may be unique to local conditions and not generalisable across countries.<sup>14</sup> Although the ICF has been extensively used in epidemiology, health systems research and clinical practices, where the focus has been on quantitative information for measurement purposes, the ICF has been widely used for collecting and conceptualising qualitative information as well (see, eg, ref 43). As a classification, the ICF is neutral with respect to data collection technique (and it is constructed to accommodate highly granular information to be fit for purpose). As a conceptual model, moreover, the ICF sets out the most general of interactive person-environment models that are essentially theory neutral and are fully compatible with highly localised and specific ethnographic, sociological or historical research.

## CONCLUSION

The ultimate goal of conceptualising the data requirements of a truly syndemic understanding of COVID-19, as a social lens for guiding policymaking and the development of effective and efficient public health measures, requires a sophisticated, interactive model that the ICF can provide. The ICF helps to identify the kinds of information that need to be collected—be it quantitative or qualitative—and in particular the range of functioning information that is as comprehensive as possible. At the individual level, ICF information can track the trajectories of post COVID-19 condition and other impacts of the disease. At the population level, functioning information is best reported using composite scores so that distributions for specific risk groups, aspects of socioeconomic status and other potential factors determining and characterising a syndemic can be quantitatively recorded over time and guide qualitatively research, in terms of what needs to be understood in depth.

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