

Exploring Large Community- and Clinically-Generated Datasets to Understand Resilience Before and During the COVID-19 Pandemic

Karen A. Monsen, PhD, RN, FAMIA, FAAN¹, Robin R. Austin, PhD, DNP, DC, RN-BC^{2,4}, Bhavana Goparaju, MS³, Robert Clarence Jones, MEd, BA⁴, Michelle A. Mathiason, MS, BA⁵, Anna Pirsch, MS, RN-BC, CLC⁶, & Milton Eder, PhD^{4,7}

1 Zeta, Professor, University of Minnesota School of Nursing, Minneapolis, MN, USA

2 Assistant Professor, University of Minnesota, School of Nursing, Minneapolis, MN, USA

3 PhD Student, University of Minnesota Academic Health Center, Institute for Health Informatics, Minneapolis, MN, USA

4 Community Liaison, Hue-MAN Partnership, Minneapolis, MN, USA

5 Statician, University of Minnesota, School of Nursing, Minneapolis, MN, USA

6 PhD Student, University of Minnesota, School of Nursing, Minneapolis, MN, USA

7 Assistant Professor, University of Minnesota, Medical School, Department of Family Medicine and Community Health, Minneapolis, MN, USA

Key words

Big data, community, COVID-19, Omaha system, resilience, social determinants of health, strengths

Correspondence

Dr. Karen A. Monsen, University of Minnesota School of Nursing, 5-140 Weaver-Densford Hall, 308 Harvard Street SE, Minneapolis, MN, 55455. E-mail: mons0012@umn.edu

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Abstract

Purpose: To explore resilience in the context of whole-person health and the social determinants of health at the individual and community levels using large, standardized nursing datasets.

Design: A retrospective, observational, correlational study of existing deidentified Health Insurance Portability and Accountability Act (HIPAA)-compliant data using the Omaha System and its equivalent, Simplified Omaha System Terms.

Methods: We used three samples to explore for patterns of resilience: pre-COVID-19 community-generated data (N = 383), pre-COVID-19 clinical documentation data (N = 50,509), and during-COVID-19 communitygenerated data (N = 102). Community participants used the My Strengths + My Health (MSMH) app to generate the two community datasets. The clinical data were obtained from the Omaha System Data Collaborative. We operationalized resilience as Omaha System Status scores of 4 (minimal signs or symptoms) or 5 (no signs or symptoms) as a discrete strengths measure for each of 42 Omaha System problem concepts. We used visualization techniques and standard descriptive and inferential statistics for analysis. **Findings:** It was feasible to examine resilience, operationalized as strengths by problem concept, within existing Omaha System or Simplified Omaha System Terms (MSMH) data. We identified several patterns indicating strengths and resilience that were consistent with literature related to community connectedness for community participants, and sleep for individuals in the clinical data. Conclusions: When used consistently, the Omaha System within MSMH enabled robust data collection for a comprehensive, holistic assessment, resulting in better whole-person data including strengths, and enabled us to discover a potentially useful approach for defining resilience in new ways using standardized nursing data.

Clinical Relevance: The notion that how we assess individuals and communities (i.e., the completeness of our assessments in relation to wholeperson health) determines what we can know about resilience is seemingly in opposition to the critical need to decrease documentation burden, despite the potential to shift from a problem deficit-based assessment to one of strengths and resilience. However, a patient-facing comprehensive assessment that includes resilience and the social determinants of health can provide a transformative, whole-person platform for strengths-based care and population management.

Whole-person health is multidimensional and complex; is composed of bio-psycho-social-spiritual elements; and may be influenced for good or ill by factors such as social, political, and moral underpinnings of societies (Berwick, 2020; Bogue, 2019; Dawes, 2020; World Health Organization, 2020). The COVID-19 pandemic of 2020 has illuminated the importance of understanding whole-person health, including resilience and the social and behavioral determinants of health, in order to respond effectively in the global crisis (Van Bavel et al., 2020). Indeed, resilience during extreme social and health-related events may be key to survival, adaptation, and transformation for individuals and communities (Abbott, Klein, Hamilton, & Rosenthal, 2009; Bradshaw, Hoelscher, & Richardson, 2007; Zamboni & Martin, 2020). Research has shown that large health datasets offer new opportunities to understand wholeperson health, including the social determinants of health (Monsen et al., 2017; Monsen, Peters, Schlesner, Vanderboom, & Holland, 2015). However, the notion of resilience has yet not been studied using such existing data. Toward the goal of optimizing the COVID-19 response interventions to support the health of populations during the pandemic, the purpose of this study was to explore resilience in the context of wholeperson health and the social determinants of health at the individual and community levels using large, standardized datasets. Our aims were 1) to describe and compare individual and community-level resilience in three large datasets; 2) to examine resilience patterns in community-generated data during COVID-19 pandemic; and 3) to examine the extent of documentation needed to classify and measure whole-person health in order to capture resilience (American Nursing Informatics Association, 2020).

Background

Recent research has attempted to illuminate the complex aspects of resilience, both at individual and community levels (Zamboni & Martin, 2020). Individual resilience is a person's ability to persevere, heal, and transform in the face of challenges, setbacks, and conflicts (Abbott et al., 2009; Bradshaw et al., 2007; Caldeira & Timmins, 2016). Community resilience is the capacity to withstand external challenges of a disaster while continuing to function, and to provide and maintain essential services, economic development, social support, information and communication, and preparedness for future events (Ayyub, 2014; Links et al., 2018; Norris, Stevents, Pfefferbaum, Wyche, & Pfefferbaum, 2008; Zamboni & Martin, 2020). To date, no studies have addressed the notion of resilience at

individual and community levels using large standardized nursing datasets.

Standardized Nursing Data for Big Data Science

There is a growing body of work substantiating the importance of standardized data to generate new knowledge in nursing and health care (Delaney & Weaver, 2019; Macieira, 2019; Monsen, 2012; Pruinelli, Delaney, Garcia, Caspers, & Westra, 2016). The University of Minnesota Center for Nursing Informatics Omaha System Partnership and Nursing Knowledge Big Data Science initiatives are leading efforts to advance the use of standardized data across settings and systems to advance knowledge discovery to improve population health (Delaney & Weaver, 2019; Pruinelli et al., 2016). Numerous previous studies have demonstrated the value of data generated by structured documentation for use in clinical trials and big data science initiatives using visualization techniques and machine learning methods for pattern discovery, hypothesis generation, and testing (e.g., Bose, Maganti, Bowles, Brueshoff, & Monsen, 2019; Gao et al., 2019; Kaya, Secginli, & Olsen, 2020; Liu et al., 2020).

Omaha System

One of the earliest efforts to develop interprofessional standardized terminologies for all of health and interprofessional health care, Omaha System research and development began in 1975 using an inductive, data-driven approach (Martin, 2005). The Omaha System is a rigorous, psychometrically robust classification system, terminology, and measure that since its inception was intended to provide a way to communicate, share, and reuse information across programs, populations, and platforms simply and taxonomically. It exists in the public domain, is mapped within the Standardized Nomenclature for Medicine-Clinical Terms (SNOMED CT) and Logical Observation Identifiers Names and Codes (LOINC), has been embedded internationally within the electronic health record (EHR) as well as other electronic platforms, and has been translated into numerous languages. Through grass roots efforts and the support of a multi-stakeholder international community of practice, the Omaha System has been instrumental in advancing research and practice to improve population health and healthcare quality. In particular, the Omaha System Partnership within the University of Minnesota Center for Nursing Informatics provides a global network of researchers, clinicians, students, and community members with opportunities to collaborate around contributed data and relevant research questions, with over 100 studies in process or completed since its inception in 2010 (Omaha System Partnership, 2021).

The Omaha System consists of three related components: the Problem Classification Scheme, the Intervention Scheme, and the Problem Rating Scale for Outcomes (Martin, 2005). The three components are psychometrically sound and are organized around the central problem list of 42 defined health concepts. The Problem Classification Scheme arranges these problem concepts into four domains: environmental, psychosocial, physiological, and health-related behaviors. Each problem concept is defined and has a set of taxonomically arranged unique signs or symptoms. The Intervention Scheme classifies the interventions that address the 42 problem concepts using one of four category (action) terms and one of 75 target terms that further specify the intervention. The four categories are teaching, guidance, and counseling; treatments and procedures; case management; and surveillance. The 75 target terms range alphabetically from anatomy/ physiology to wellness and reflect common topics, various disciplines, and frequently employed activities across the spectrum of health care. The Problem Rating Scale for Outcomes is a set of three Likert-type ordinal scales for three dimensions of problem concept-specific outcomes: knowledge, behavior, and status. All three scales range from 1 (lowest or worst) to 5 (highest or best). Together these three components enable the learning health system cycle to generate high-quality data for clinical use and for rigorous study of these data to improve healthcare quality and population health outcomes.

My Strengths + My Health

A consumer-facing health assessment app that incorporates the Omaha System, My Strengths + My Health (MSMH) is a web-based mobile optimized application designed through extensive testing in community settings (Figure S1; Austin, 2018). Because it is based on the Omaha System it is a comprehensive, holistic assessment tool that incorporates a whole-person perspective through the rigor of the Omaha System's simplified plain language terms, and it is highly secure, being hosted within the university's protected data storage and analysis shelter. Licenses are freely available for clinicians, educators, and researchers. Each study license instance has a study dashboard and the ability to download complete study data. MSMH is available in English, with translations in progress for Spanish, French, Russian, and Mandarin.

Omaha System Definitions of Whole-Person Health, Social Determinants of Health, and Resilience

The terms and definitions of standardized nursing terminologies such as the Omaha System are a granular set of concepts that together describe a comprehensive, holistic conceptual framework for health (Martin, 2005). These terms and definitions may be used to operationally define and represent more complex concepts such as the social determinants of health, health literacy, and wellbeing (Monsen, 2018; Monsen et al., 2015; Monsen et al., 2017; Michalowski et al., 2018). Conducting advanced exploratory analyses using data generated by standardized nursing terminologies is possible because this rigorous definitional work was completed a priori (Martin, 2005; Monsen, 2018). In this study, our operational definition of whole-person health means understanding all of health across all Omaha System concepts and domains, inclusive of strengths (Problem Rating Scale for Outcomes Status scores), challenges (signs or symptoms of the 42 problem concepts), and needs (intervention category terms; Figure S2). We operationalized the social and behavioral determinants of health as the concepts in three domains: environmental (my living, n = 4), psychosocial (my mind and networks, n = 12), and health-related behaviors (my self-care, n = 8). We operationalized resilience as the number of strengths for problem concepts having a status score of 4 (minimal signs or symptoms ["good" in MSMH]) or 5 (no signs or symptoms ["very good" in MSMH]). We aggregated strengths assessments for the population of interest to understand the resilience of a particular community or group.

The purpose of this study was to explore resilience in the context of whole-person health and the social determinants of health at the individual and community levels using large, standardized datasets. Our aims were (a) to describe and compare individual- and community-level resilience in three large datasets; (b) to examine resilience patterns in community-generated data during the COVID-19 pandemic; and (c) to examine the extent of documentation needed to classify and measure whole-person health in order to capture resilience.

Methods

This retrospective, observational, correlational study of existing data was determined to be exempt by the University of Minnesota Institutional Review Board. The instrument was the Omaha System and its plainlanguage equivalent, Simplified Omaha System Terms. All data were stored in a university-provided secure computing environment and analyzed as described by aim. We explored the three datasets to identify patterns in resilience, pre-COVID-19 community-generated data, pre-COVID-19 clinical documentation data, and during-COVID-19 community-generated data. All data were de-identified and Health Insurance Portability and Accountability Act (HIPAA) compliant; it was not possible for the researchers to re-identify any individual from the data.

Pre-COVID-19 Community-Generated Data (Community; N = 383)

Data were generated in the community by volunteer participants at a large metropolitan state fair using MSMH. Fairgoers received a string backpack gift valued at less than \$3.00 for participation.

Pre-COVID-19 Clinical Documentation Data (Clinical; N = 50,903)

Nurses and other healthcare practitioners in community care settings generated clinical data during routine documentation. Data were contributed to the Omaha System Data Collaborative by member organizations. Clients were served primarily for home care and public health nurse maternal or child health programs.

During COVID-19 Community-Generated Data (COVID-19; N = 102)

Data were generated in the community by volunteer participants during the 2020 COVID-19 pandemic using MSMH. Recruitment was virtual with no face-to-face encounters. Respondents received a modest gift for participation (e-gift card delivered by e-mail). We conducted analyses for all aims using R Studio IDE for R (Revelle, 2020; Version 2.0.9; Wickham, François, Henry, & Müller, 2020; Version 1.0.2).

For Aim 1, we calculated percentages of problem concepts rated as a strength (>3 points on a 5-point scale) among all who rated the problem concept to identify the most frequent strengths. We analyzed co-occurrences of various strengths using the Pearson correlation coefficient varying from -1 (perfect negative association) to +1 (perfect positive correlation). The higher the correlation between any two items, the more often they co-occurred as a strength for a given individual (Upton & Cook, 2014). We calculated percentages of each sample with strengths by problem concept to enable comparisons across three datasets.

For Aim 2, we displayed the strengths in a correlation matrix by problem concept for the three datasets to visualize patterns in the correlations of resilience across problem concepts. To create the heat maps, we used conditional formatting functionality in Excel applied to each correlation matrix with a three-color scheme denoting relatively most positive (blue) vs. relatively most negative (red) correlations across all problem concepts.

For Aim 3, to examine assessment patterns in MSMH and clinical data, we calculated the percentages of those problem concepts having strengths when assessed, and the number of other concepts assessed when a given concept was a strength. Given that the COVID-19 study was limited to 20 problem concepts, we conducted our analysis of documentation patterns using the two pre-COVID-19 datasets. We conducted analyses for all aims using R Studio IDE for R (Revelle, 2020; Version 2.0.9; Wickham, François, Henry, & Müller, 2020; Version 1.0.2).

Results

Results are presented by aim with accompanying visualizations (Table S1 to Figures S3 and S4).

Aim 1

Overall, there were many strengths across all datasets (see Table S1). We identified differing patterns in strengths by problem concept across the three datasets. There were fewer strengths by problem concept across domains in the clinical and COVID-19 data compared to the community data. For community, an average of 77% of the sample self-reported a given concept as a strength, ranging from sleep and rest patterns (30%) to pregnancy (99%). For clinical, an average of 68% of the sample had a given concept documented as a strength, from grief (14%) to spirituality (95%). For COVID-19, an average of 64% of the sample self-reported a given concept as a strength, ranging from income (33%) to neighborhood or workplace safety (84%).

Comparing across datasets for a threshold of 75% of respondents with a strength, three problem concepts reached this threshold across the three samples: neighborhood or workplace safety, abuse, and communicable or infectious condition (see Table S1). The community data had the highest percentage of concepts meeting this threshold (28 of 42, 67%), compared to the clinical data (13 of 42, 30%) and the COVID-19 data (7 of 19, 36%). The community data had more strengths by concept (74%) than the COVID-19 data (64%), (t = -2.49, df = 19, p = .022). Comparing community

and COVID-19 differences, there were notably fewer strengths in income and social contact during COVID-19, both of which are recognized as impactful social determinants of health (see Table S1; Institute of Medicine [IOM], 2014; Monsen et al., 2017).

Aim 2. Resilience Patterns

Results of the exploratory analysis of inter-problem concept strengths using heat maps are shown in Figure S3. In Aim 2, we identified two additional distinct resilience patterns that differed by setting (community vs. clinical). For community (upper heat map), a single problem concept, communication with community resources ("Connecting" in MSMH), was found to uniquely correlate with other problem concepts when identified as a strength, compared to all other problem concepts. Most strengths problem concepts correlated within their domains as seen by the blue triangle shapes, revealing intradomain positive correlations. For clinical (middle heat map), a single problem concept, sleep and rest patterns ("Sleep" in MSMH), was correlated with having many other strengths. Interdomain correlations seen in the community data heat map were not identifiable in the clinical heat map. For COVID-19 (lower heat map), the communication with community resources strengths pattern observed in the community data was also present in the COVID-19 pandemic data.

Aim 3

In Aim 3, we explored the distribution of concept assessments in clinical data relative to having a strength in a given concept, using line graphs (see Figure S4). We observed that documentation patterns varied greatly between community and clinical data. In the community data, on average, 219 of 383 (57%) responded to a problem concept in MSMH, and of these, 77% rated the concept as a strength. In the clinical data, on average, a concept was assessed for 5,655 of the 50,906 cases in the sample (11%), and of these, 69% rated the concept as a strength. Concepts assessed between MSMH and clinical documentation differed greatly, as seen in the upper section of Figure S4 (57.2 vs 7.6, respectively; p < .001). Despite the high percentages that had strengths for both community (77%) and clinical documentation (69%), these percentages differed (p = .01, middle section of Figure S4), as did the percentages of the overall assessment completed when each concept was assessed as a strength (28.6% vs.12.2%; p < .001, lower section of Figure S4).

Clinical assessments were more likely to be targeted for maternal health clients, such as pregnancy,

postpartum, growth and development, and caretaking or parenting. In the clinical data, many concepts that were rarely assessed (e.g., spirituality [with 28 other concepts assessed], consciousness, and speech and language) were part of a very comprehensive assessment that included high numbers of other concepts (see Figure S4). In community data, five concepts in three of four domains (psychosocial domain: spirituality, abuse, neglect; physiological domain: reproductive function; and environmental domain: neighborhood or workplace safety) were more than 90% likely to be strengths when they were assessed. Thus, in both datasets, the less frequently that documented problem concepts were assessed or reported, the more likely they were to be strengths.

Discussion

Using large community- and clinically-generated datasets and a data visualization exploratory approach, we identified patterns that may represent individual and community resilience, both before and during the COVID-19 pandemic. Across all aims, we found it was feasible to examine resilience operationalized as strengths by problem concept within existing Omaha System or MSMH datasets. The communication with community resources pattern of correlated strengths was consistent across community datasets, suggesting that Omaha System assessments may offer a simple yet meaningful measure of resilience when the assessment includes this problem concept. Furthermore, findings demonstrated that the Omaha System within MSMH could be used consistently by consumers for a whole-person assessment and could reveal valuable insights about resilience at the population level. Perhaps most importantly, we explored the notion that how we assess individuals and communities (i.e., the completeness of our assessments in relationship to wholeperson health) determines what we can know about resilience.

A number of interesting patterns emerged from these analyses. Both communication with community resources (community) and sleep and rest patterns (clinical) findings align with what is known in the literature (Amobi, Lewis, Novais, & Alexander-Scott, 2019; Seelig et al., 2016). These findings are actionable and point to strengths-based intervention approaches. For example, communities can improve and support resilience through addressing any barriers or gaps in community resources. This is especially important during extreme circumstances when resources for essential needs may become scarce. The sleep pattern aligns with research showing that sufficient high-quality sleep underlies and supports good health, and reinforces the need for healthcare practitioners to assess sleep consistently in routine healthcare encounters, intervening as needed to help optimize sleep quality and duration. We further discovered evidence that strengths in neighborhood or workplace safety were prevalent in all three datasets, despite challenges faced by many communities during the first several months of the COVID-19 pandemic. While this is encouraging, we must consider the importance of reaching out to underserved communities in order to ensure that we understand strengths, challenges, and needs in all neighborhoods, not just those that voluntarily participate in research (Fiske, Prainsack, & Buyx, 2019; Rothstein et al., 2020). The finding that recognized social determinants of health concepts income and social contact differed between pre-COVID-19 and during-COVID-19 community data lends credibility to our findings given the impacts of COVID-19-related workforce changes and social distancing on individuals (IOM, 2014; Monsen et al., 2017). The patterns identified in the continuum of assessments discovered in our clinical data may reflect different practice patterns and clinical assessment protocols that reflect and are responsive to policy decisions, and may vary due to documentation burden. Further research is needed to confirm these patterns in additional datasets across practices, populations, and programs.

In assessing the extent of documentation needed to understand resilience, it was evident that more documentation was better: a complete whole-person assessment that included most or all of the Omaha System problem concepts was highly likely to reveal strengths. Together these findings support the feasibility of the Omaha System in MSMH and EHR-generated data to describe whole-person health, and to inform both individual and community decision making, clinical care, and policy development. We have long known that it is critical to embrace this shift from a problem or deficit-based perspective toward an empowering strengths and resilience approach in order to change health care's dominant deficit model, with its negative consequences on health (Sturgeon & Zautra, 2010; Yeung, Arewasikporn, & Zautra, 2012). This study provides evidence that such a shift in perspective is possible, especially with the advent of robust consumerfacing assessment tools such as MSMH, which places the person at the center, captures whole-person health, and alleviates documentation burden for the clinicians. We would be remiss to argue for a comprehensive (42-concept) whole-person assessment by practitioners simply because we would like to better understand strengths as well as challenges and needs in our patients and communities. Rather, we need to consider novel solutions for blending patient-generated data with clinical observations for a more balanced perspective that includes strengths, challenges, and needs. We can accomplish this when we empower patients and communities to contribute data, and when we value that data in our clinical, social, and political interactions.

While we do not claim that this study is either conclusive or generalizable, we believe that we have established strong evidence for using MSMH and the Omaha System to identify resilience across settings and platforms. This is particularly important during the pandemic so that those of us in stigmatized or underserved communities may point to our own strengths as well as our needs and challenges, incorporate strengths into our narratives, and advocate for meaningful policy changes to support communities and neighborhoods where interventions can do the most good to address the pandemic. The next steps are to continue building community relationships, sharing these findings with community partners to advance meaningful community-partnered and community-led initiatives around resilience during the pandemic and beyond.

The limitations of this study are common to all retrospective studies, and findings should be interpreted with care. It was beyond the scope of this study to delve further into patterns among strengths, challenges, and needs. This work is ongoing, with the purpose of continuing to advance the study of whole-person health, including ways to leverage strengths to improve health.

Conclusions

In this study we demonstrated the value of standardized assessments across communities, clinical settings, and over time (before and during COVID-19) for understanding patterns of resilience. Furthermore, our findings emphasized the importance of resilience as a way to work within communities to address the challenges we face during extreme circumstances. The paradigm shift to one of resilience is long overdue; therefore, let us begin.

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Clinical Resources

- My Strengths + My Health. Obtain license. https://www.mystrengthsmyhealth.com/
- The Omaha System. http://omahasystem.org/
- Omaha System Guidelines. My Strengths + My Health. https://sites.google.com/view/omaha systemguidelines/mystrengths-myhealth?authu ser=0
- Omaha System Partnership. http://omahasyste mpartnership.org/

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Supporting Information

Additional supporting information may be found in the online version of this article at the publisher's web site:

Figure S1. My Strengths + My Health application.

Figure S2. Whole person health for individuals and communities, with social strengths (resilience), challenges (signs/symptoms), and intervention needs determinants of health, and intervention needs.

Figure S3. Heatmaps of strengths correlations.

Figure S4. Analysis of assessments in clinical vs. community data.

Table S1. Percentages of Strengths by Problem Concept for Community, Clinical, and COVID-19 data, With Differences in Community and COVID-19 Datasets.