

Piloting a Big Data Epidemiology Approach to Support Frail, Homebound, and Bedridden People

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Abstract. Frail, homebound, and bedridden people (FHBP) are people living at home whose daily life is physically limited to the boundary of their houses because of their ongoing health, energy, and psychosocial or socio-functional impairments. This definition needs a scientific, systematic, and data-driven view of the distribution (frequency, pattern) and determinants (causes, risk factors) of health-related states and adverse events experienced by FHBP. Thus, we piloted a big data epidemiology approach (Multiple Correspondence Analysis and data visualization) from 300 survey responses about FHBP experiences and identified a positive correlation between perceived health status and reported impairments.

Keywords. Big data epidemiology, frail, homebound, bedridden, public health

1. Introduction

Responding to health consumers' calls, during July-September 2020, we conducted an online survey (Qualtrics opt-in link) snowball-shared via advocacy groups and social media to investigate the experiences of FHBP. The inquiry was relevant because, according to the Australian Bureau of Statistics, in 2018, approximately 596,800 people were not leaving home as often as they would like due to disability and/or health conditions [1-3]. So, further investigation was requested to support reports of FHBP adverse experiences around the impairments and circumstances that marginalize them from receiving primary care as their conditions are not recognized as disabilities or seen as support worthy by current standards [1-3].

The survey was approved by the Flinders University Social and Behavioral Research Ethics Committee (Project No. 8557), and 152 people responded to the quantitative aspects of the study and 300 to the qualitative questions. FHBP reported experiences of multiple comorbidities and social isolation. They highlighted their need to access the health system through telehealth and clarified the need to move beyond patients' physical

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attendance [1-5]. Using such data, this study aims to pilot a big data epidemiology approach to identify a group of FHBP with a similar profile in their answers to the questions and possible associations between variables and categories of the survey.

2. Methods

To pilot a big data epidemiology approach to support FHBP, we use rigorous quantitative data analysis by running a Multiple Correspondence Analysis (MCA), which can be seen as a generalization of principal component analysis. We used the *FactoMineR* and *factoextra* packages of R software for the visualization of possible distribution and components of health-related states and adverse events experienced by FHBP [6-8].

3. Results

Figures 1 and 2 show the biplot and quality on a factor map of the MCA (respectively) corresponding to the data set (people and variables, summarized in Table 1 as per the available report [4]. Figure 2 presents associations between the considered variables/categories concerning FHBP. The distance between points or triangles in Figure 1 gives us a measure of their similarity or dissimilarity. Some of the variable categories only appear in the picture by overlapping. Despite the low variability representation (13.62%) of the two dimensions of the MCA factor map, we can highlight some relationships between variable categories. For example, people who answer that they are currently homemakers (Q46_5_1) or looking for work (Q46_3_1) tend to be needing the help of another person for transferring (Q41_6_1). Additionally, according to the representation and location of the variable categories, people that have four or more hospital admissions (Q27_4_1) and have a learning disability (Q42_7_1), refers to need the help of another person for toileting (Q41_5_1) and bathing (Q41_1_1).

Table 1. Summary guide of variables description [4].

Column	Code	Description
14	Q3	Difficulty getting around at home or outside your home.
15	Q4	Mobility assistance device to move around at home or outside your home
16	Q5	Help from another person to move around, inside or outside your home
17	Q6	Unable to leave the house most or all of the time.
18	Q7	Stay in bed most or all of the time
19	Q8	Are you permanently unable to leave your home
20	Q9	Do you permanently need to stay in your bed
36	Q11	Filter question
37	Q12	People description (free text)
42	Q13	Describe the situation (free text)
43-54	Q15	Have you experienced
56	Q16	Free text
57-73	Q17	Consider it important to help you or other Australians.
76-83	Q50	Relevant experience concerning the ambulance and hospital services
88-94	Q49	Do you struggle to
126	Q24	How many chronic conditions do you have
127-132	Q25	Different prescription drugs you need to take each day
134-137	Q27	The number of hospital admissions and unplanned re-admissions

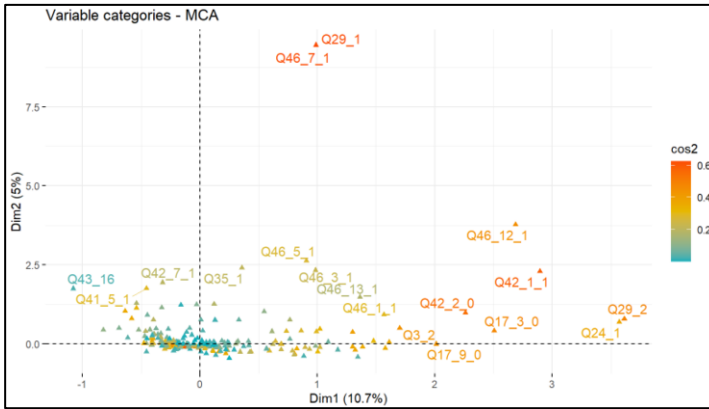


Figure 2. Quality on the factor map.

Figure 3 displays Goodman and Kruskal's tau correlations plot for some of the considered variables in the study; it shows that the current situation or impairments that best describe people's situation (Q42) positively correlate with how they compare their health status with people their age (Q29).

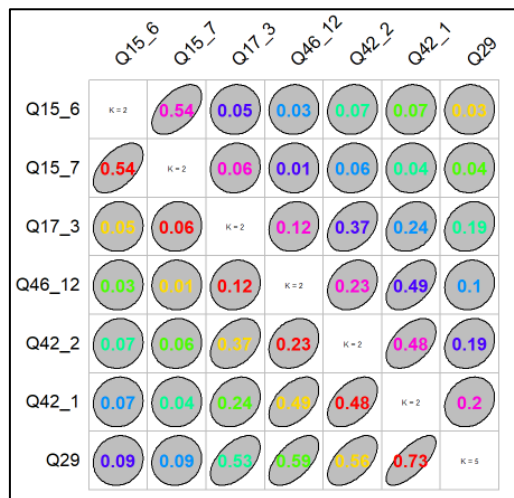


Figure 3. Goodman and Kruskal's tau correlations. K values represent the number of levels for each variable, and values inside of ovals represent correlations between variables. Note that this correlation is not symmetric.

4. Discussion

The issues reported by FHBP (disseminated elsewhere), [1-5] inform our analysis, particularly the positive correlation of current FHBP's impairments with the way FHBP compare their health status with people their age (i.e., 85% of respondents think their health is much poorer when compared to people their age) [4]. These perceived health items can correlate with functional decline, morbidity, and mortality, unveiling help-

seeking behaviors and health services utilization [9,10]. Hence, further investigation is required to eventually, create regulatory measures against negative patterns experienced by FHBP.

5. Conclusions

A deeper big data epidemiology approach should be developed [11], involving collaboration with experts from socio-medical fields [12]. FHBP aspire to instigate change by seeking recognition as a united group, an active network of individuals, rather than being categorized solely as another subgroup of disempowered patients, defined and isolated by their most symptomatic disease. Such a development has the potential to introduce diverse perspectives and tools for addressing complex public health issues, with a primary focus on improving people's socio-medical experiences [1-5,13,14].

References

- [1] de Plaza MP, Beilegoli A, McMillan P, Clark R, Visvanathan R, Kitson A. Australian primary care reform requires co-designed Telehealth-based care for its homebound population. In 21st Successes and Failures in Telehealth Conference: 13th Annual Meeting of the Australian Telehealth Society 2021.
- [2] de Plaza MA, Beilegoli A, Mudd A, Tieu M, McMillan P, Lawless M, Feo R, Archibald M, Kitson A. Not well enough to attend appointments: Telehealth versus health marginalisation. In The Australasian Institute of Digital Health-Digital Health Institute Summit 2020: Uniting the digital health movement in 2020, one of the health sector's most challenging years. 2021 Apr 19 (pp. 72-79). IOS PRESS.
- [3] de Plaza MA, Beilegoli A, Brown S, Bulto LN, Gebremichael LG, Nesbitt K, Tieu M, Pearson V, Noonan S, McMillan P, Clark RA. Effectiveness of telehealth versus standard care on health care utilization, health-related quality of life, and well-being in homebound populations: a systematic review protocol. *JBI Evid Synth.* 2022 Nov;20(11):2734-42, doi: 10.11124/JBIES-21-00410.
- [4] de Plaza MA. Making the Invisible Visible: Exploring the Experiences of Frail Homebound and Bedridden People: Preliminary Research Report for the Community. In Consumers Health Forum Virtual Summit 2021: Shifting Gears 2021 Apr 16. Flinders University.
- [5] de Plaza MA, Dafny H, Lawless M, McMillan P, Buchanan R, Leon Z, Beilegoli A, Archibald M, Mudd A, Lange B, Tieu M. ENLIGHTEN: homebound people aging with Technology: Holding the suspension bridge of ongoing high-quality care. In 55th Australian Association of Gerontology (AAG) Conference: The future of ageing well 2022 Nov 22.
- [6] Husson F, Josse J, Pages J. Principal component methods-hierarchical clustering-partitional clustering: why would we need to choose for visualizing data. Applied Mathematics Department. 2010 Sep;17.
- [7] Kassambara A, Mundt F. Package 'factoextra'. Extract and visualize the results of multivariate data analyses. 2017;76(2).
- [8] Pearson R. Goodman-Kruskal: association analysis for categorical variables. R package. 2016.
- [9] Idler EL, Kasl SV. Self-ratings of health: do they also predict change in functional ability?. *The J Gerontol B Psychol Sci Soc Sci.* 1995 Nov;50(6):S344-53, doi: 10.1093/geronb/50B.6.S344.
- [10] Galenkamp H, Braam AW, Huisman M, Deeg DJ. Self-rated health: when and how to use it in studies among older people?. *International handbook of health expectancies.* 2020:173-81, doi: 10.1007/978-3-030-37668-0_12.
- [11] Health UDo, Services H. Principles of Epidemiology in Public Health Practice Third Edition An Introduction to Applied Epidemiology and Biostatistics. 2020.
- [12] Pinero de Plaza MA, Yadav L, Kitson A. Co-designing, measuring, and optimizing innovations and solutions within complex adaptive health systems. *Front Health Serv*;3:21.
- [13] Pinero De Plaza MA, Conroy T, Mudd A, Kitson A. Using a Complex Network Methodology to Track, Evaluate, and Transform Fundamental Care. *Stud Health Technol Inform.* 2021 Dec;284:31-5, doi: 10.3233/shti210656.
- [14] de Plaza MP, Beilegoli A, McMillan P, Clark R, Visvanathan R, Kitson A. Australian primary care reform requires co-designed Telehealth-based care for its homebound population. In 21st Successes and Failures in Telehealth Conference: 13th Annual Meeting of the Australian Telehealth Society 2021.