

How “BIG DATA” Works During the Collaborative Care for Elderly

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As World Health Organization’s definition, a healthcare system consists of all organizations, people and actions whose primary intent is to promote, restore or maintain health. It is, therefore, more than the pyramid of publicly owned facilities that deliver personal health services. It includes, for example, a mother caring for a sick child at home; private providers; behaviour change programmes; vector-control campaigns; health insurance organizations; occupational health and safety legislation, and so on. In our case, we pay our attention to the intrastructuring work of elderly and their caregivers.

Nowadays aging of population has become an inevitable trend, which gives out a tough task of caring for the aged. Similar to other health care work, various healthcare systems are embedded into the aging caring process, and influence determinants of health as well as more direct health-improving activities for elderly. In the rapidly developing digital era of health, all these functions, almost without exception, cannot be come true without the support of big data. Many researchers and health practitioners are involved into the research of data-based health care. In our study, what we focus on is the issue of how BIG DATA works during the collaborative caring process for elderly, especially from the perspective of care providers. We conducted a series of qualitative study in the last six months in Shanghai, China, to explore this issue. In what follows, we will describe the breakdowns and challenges we found in our case from the perspectives of elders, care providers, family and managers respectively.

The general described scenario is as follows: data (including elders’ personas and activities of daily living, health record, caring activities etc.) is collected through both auto collection (e.g. via sensors and mobile devices) and manual collection. This collected data services different roles who are involved into the caring process. For instance, care providers could learn the basics, caring needs, and notice of their service elders directly and provide the appropriate services for them; the publicly owned facilities could deliver appropriate health services; the policy maker could learn the overall level of aging caring; and the researchers could mine and analyze this data to identify more caring related issues. All of these generate better care for elderly finally. In this scenario, data, no doubt, provides more perspectives and more reasonable evidences for different roles.

Yet, when we understand the data-working process from the perspective of front-line care providers, we found while the collected data do help to generate more appropriate health services for elders, there are some problems that cannot be ignored.

- *Over emphasized BIG data and ignored SMALL data.* Influenced by the rapidly developing digital era of health, many old-age care institutions follow the big data trend, and shape the big data as the basic of development. Various datasets are conducted to collect data as much as they can. Much small data, however, is

ignored. For instance, for one elder, his/her daily health data, activities of living, personas, are all very important and collected as the part of big data. Yet, what one of his/her action, sound or expression means is also very important to the health care. Even, these caring details could influence the caring quality directly.

- *Over emphasized professional data and ignored common data.* Learning how to care is the basic step for the training of care providers. In our study, we took part into several training courses and found the trained contents are mainly the professional knowledge, such as “what should we do if the older fell down”. Yet, the special cases such as felling down are all-too-rare events. What more common is what the older likes to eat, or what show he/she like to watch. This common data is usually ignored.
- *Experienced data feeds big data.* What we expected is using big data to support better caring services. Yet, for the front-line care providers, it is more like collecting data for big data and using experienced data to feed big data, which does not support better caring services, but improve the caring cost. One common scene we observed in our study is, they are required to record the data as much as they can, but their daily caring work is so busy. Hence, they would not record the caring data during the caring process. Instead, they do that at break time based on their experiences and memory.

Given these problems, we are exploring the possibility of the development and usage of “personalized” caring platform based on the “personalized” dataset for each elder. In this “personalized” caring platform, the priority showing content is the common and experienced data about this elder, such as his/her preferred way of communication, what does his/her dislike, and what is his/her habits and so on, instead of the structured health data. We believe these datasets could quickly influence the caring process and improve the caring quality. The key issues emerging from this platform are a) the way of collecting this common and experienced data, with the lowest collecting cost, and b) the interactive way of this platform with good experience for its possible users. We hope to open the discussion about these issues.