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Citizen Science approach and Datification: Pilot Study on Factors Influencing the Dementia among Older Adults

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Abstract: *This pilot study examined the contribution of citizen science approach to the datification of factors influencing the progress of cognitive health of the older adults. Newspapers were reviewed and FGIs of field workers at a Day Care Center gathered relevant data from citizen. Two questions were put forward; whether new factors are drawn from citizen knowledge; if yes, whether they represent a new type of data. 'Aesal', personality of the older adults with dementia is noted as a new dementia affecting factor. The data on personality also present a new challenge for scientific measurement. The relationship between personality or psychology of the older adults and the risk of getting dementia has been a research field for a long time, yet the impact of personality on the progress of dementia has not been examined scientifically. Because of communication difficulties with the older adults with dementia, new types of indicators and new ways of measurements thus need to be developed.*

Keywords: Citizen Science; Datification; Dementia; Practitioners

1. Introduction

The ratio of senior population over 65 years old in Korea has passed 14% milestone in 2017, indicating it having been an aged society already, and the ratio will reach 20% in 2026, meaning it becoming a super- aged society in less than 10 years [1]. The current state-governed, expert-centered, and supplier-dominated older adults health care service system would not be able to meet the growing demand with such an alarmingly fast speed [2]. The 'active ageing' principle, namely more active role of the older people themselves in managing health in the later stage of life, is encouraged and emphasized to address this issue [3]. The community support system for health management of the older people and their family, and the preventive approach to healthcare are pursued as a way forward [4].

Citizen science, a research approach that engages non-professionals and practitioners in the process of creating new knowledge [5], may prove to be useful in helping implementing the active ageing principle. The participation of the older people in health/care science research process would contribute to the production of new and useful knowledge. For instance, since most of senile diseases such as dementia are chronic and their management is more dependent on the behaviors of the patients rather than medicine, the older people themselves may possess more relevant information than experts [6]. Practitioners such as care workers may turn out to be an overlooked yet crucial source of tacit knowledge embedded in care places. Citizen science approach may facilitate the revelation and utilization of new types of data which could open a new line of scientific enquiry.

he participation of non-professionals in scientific research process, however, poses several challenges. The information, anecdotes and experiences of the older person and care workers would not be recognized as scientific knowledge automatically. They should stand the rigors of scientific scrutiny of the experts. The observations and contributions from non-professions may turn out to be mere local variations of existing knowledge. In some cases, the participating older people or practitioners may not agree with the assessments by the scientists.

This paper aimed to introduce the findings from a citizen science pilot project on factors influencing the progress of cognitive health (dementia) of the older adults. The main research question was whether there are new knowledge contributions from citizen as to factors influencing the progress of dementia. Information from newspapers and focus group interviews of care workers were gathered and analyzed as source of citizen knowledge. Experts and non-professionals together assessed the originality, validity and utility of those information to draw new findings regarding factors influencing the progress of dementia.

First, as a way of building analytical framework and structure of pilot project, main aspects of citizen science approach discussed; its definition, process, mechanisms and challenges. Second, details of the pilot project were introduced and research findings were explained and discussed. The task of citizen science, in particular that of keeping data quality further discussed. It concludes with policy implications along with future research direction.

2. Citizen Science: opportunities and challenges

Initially non-professionals or citizens participated in scientific research as an observer or monitor of targeted phenomenon, for example, bird counting [7]. Citizen takes an instrumental role in these traditional expert-centered scientific research. In other cases, however, citizen takes more active role by initiating research and engaging in it at an earlier stage [8]. For instance, the concern of ordinary people about environmental problems such as air pollution or radiation from nuclear waste prompted civic movements and led to scientific enquiries. Citizens take an initiative in a new knowledge production activity as well as be mobilized to perform a scientific research.

Citizen science, therefore, can be differentiated according to the level of participation. As Table 1. shows it can be classified into 4 groups; crowdsourcing science, distributed intelligence science, participatory science and extreme collaborative science [9]. In other words, non-professional citizen can take part in each stage of scientific research production process from defining problem/question stage to building and refining research framework, doing experiment, collecting and analyzing data to interpreting and discussing results [9].

Table.1 Levels of Participation and Engagement

Level	Engagement Action
Level 4 *Extreme*	*Collaborative Science* Problem Definition, Data Collection & Analysis
Level 3 *Participatory*	*Participatory Science* Problem Definition and Data Collection
Level 2 *Distributed Intelligence*	*Citizen as basic interpreters* Local Knowledge Provider
Level 1 *Crowdsourcing*	*Citizen as Sensors* Monitoring, Volunteered Computing

The multiple levels of participation infer fundamental knowledge basis of citizen science. Citizens do have knowledge and capability to contribute to the scientific knowledge production. They can provide local knowledge which experts may not possess. Real life experiences and field practices may provide a different context from scientists' laboratory, within which new kinds of knowledge would emerge and be accumulated in ordinary people. They can also present different interpretation in relation to the research data and findings. The tacit nature of knowledge enables ordinary people to contribute to the creation of new knowledge [10]. What citizen science approach does would be to mine tacit knowledge embodied in ordinary people and make it explicit.

Citizen science project, therefore, is not necessarily dominated by expert scientists [11]. It is a collaboration between experts and lay person but also can be a conflict among them. It is quite certain that non-professional citizens will learn from expert scientists during the project, yet it is also true that scientist may learn from the participating citizens. It is the interaction among scientists and lay person that citizen science project adds to the conventional knowledge production process. The initiative and capability of citizen should influence the degree of the interaction and learning among the participants while scientific scrutiny sets the context of the citizen science project.

The issue of data quality may be the case in point, which has been regarded as an intrinsically vulnerable aspect of citizen science. Within established scientific disciplines such as ecology and environmental science, where the manual of data collection and analysis is standardized, training of citizen participants among other things is the key methods to keep data quality [12,13]. Yet it might be problematic in area where new types of data, new methods of data collection, or new frameworks of understanding is continuously emerging. Under such circumstances, citizens may provide novel types of data which require a new manual of data collection and analysis. For instance, health data in the era of 'datification' throw new challenges regarding data quality [14,15]. Digital technology enables users to collect various types of data in large scale at any time they want [16]. In connected online world, individuals are now regarded as 'a walking data generator'. Production of Health data is no longer confined to hospitals or doctors' lab but can be obtained through diverse interfaces of individuals' life. Production of good quality data is one of the critical challenges of data economy along with other ethical issues related to privacy or A.I. mediated decision making [17].

The question of the pilot study on the factors influencing the progress of cognitive health of the older adults with citizen science approach, thus can be summarized into two. First, whether new knowledge contribution is made by citizen participants; Second, if yes, whether they are based on new types of data. Next section introduces the pilot study and discusses research findings; a new factor affecting the progress of dementia, 'personality' of the older adults.

3. Factors influencing the progress of cognitive health of the older adults with dementia

3.1 Pilot Study

The objective of pilot study was to seek out new factors which affect the cognitive health of the older adults using citizen science approach. There were numerous studies on this subject and quite a number of factors have already been identified; Socio-demographic factors such as age, sex and education level; Biological factors such as genetic information, hereditary disease history, cerebrovascular disease, depression and high blood pressure; Personal factors such as smoking, drinking and diet; Social lifestyle factors such as leisure activity, relationship with friends and social network. National Institute of Dementia of Korea (NID) has developed 'dementia prevention and management tool' and supplied online app called 'Chimae Check' in which 13 factors are identified as key activities for the prevention and the progress of dementia [18]. Expert knowledge on dementia-affecting factors are well researched.

To seek out the factors from citizen knowledge pool, two methods were employed; review of newspapers and focus group interviews (FGIs) of caregivers for the older adults with dementia. After Big KINDS DB of Korea Press Foundation was searched with key word, dementia and prevention. 919 newspaper articles were found in the year 2019 from which 122 factors were identified.

In relation to FGIs, 6 caregivers (6 women in their 50s) and 6 social workers (2 men in their 20s, 3 women in 30s and 1 woman in 50s) at Rafael Day Care Center for the older adults participated in the discussion on two occasions in May, 2020 (around 1hour session each on the 12th and the 27th). While social workers were regarded as professionals, caregivers were counted as semi-professionals in FGIs. The participation of the older adults with dementia themselves is not plausible because of the obvious communication problems. Yet what should be noted is that since Rafael Day Care Center with maximum capacity of 40 persons enrollment has been in operation for the last 5 years and caregivers and social workers have enough chances to observe the progress of dementia and the factors affecting it. Although they were not exactly non-professionals or lay person, they did represent the 'citizen' as holders of local knowledge in real life context and field-practice context.

3.2 Personality as a new factor affecting the progress of dementia

Results from newspaper analysis and FGIs were put forward in front of expert panels and examined. A Neurosurgeon, an university professor and social workers specializing in caring for the older adults, an

university professor of statistics and a research fellow for science & technology policy investigated the methodology, results and compared identified factors with existing body of knowledge on dementia. This expert panel plays the role of scientific scrutiny filter through which the quality of citizen-originated data was checked and the interaction with citizen knowledge was taking place.

Most of newspaper articles referred scientific research findings or dealt with expert interviews. Out of 122 factors drawn from the newspaper analysis, only 21 factors were identified with real life experiences and field practice; Habit of note-taking, objects of memories, habit of physical exercise and playing game or habit, were emphasized as factors influencing the progress of dementia in patient case stories or column of journalists. Social factors such as participation in day care program or education program was also mentioned. The existence of village community where the older adults were residing proved to be always beneficial to the management of the dementia. Table. 2 illustrates the factors from the reviews and FGIs. All these factors are worthwhile to observe and pay attention to, yet they are not exactly new findings in relation to the dementia management.

Personality of the older adults with dementia, however, has not been scientifically seriously looked at so far. While factors drawn from FGIs showed similar features of those from the newspaper review such as habit of exercise, existence of close kin and conversation companion and taking a walk, 'Personality' stand out as a new factor. The older adults' self-management capability, positive attitude, stress control capacity and selfishness were identified as influencing cognitive health, which were grouped into the notion of personality. Caregivers and social workers at Rafael Day Care Center, through their experiences in caring for the older adults for more than 4 years, realized and concluded that certain feature of the older adults, 'Aesal' in Busan dialect, did affect the speed of the dementia progress. If someone has 'Aesal', it means that he/she has a very competitive attitude and does his/her best in everyday activities. In Rafael center, a group of 5 older adult members with Aesal personality have maintained stable condition over the years while the other 5 members with less Aesal seemed to be in continuous decline. They have all participated in day care center programs, taking a walk, playing games and hobbies, yet their condition of cognitive health had displayed rather divergent patterns according to their personality.

Upon two levels, 'personality' as a factor would add to the existing body of knowledge on dementia studies. First, dementia-affecting factors are usually researched as a separate entity or external action impacting on the older adults. Numerous prevention and treatment methods revolves around lifestyle recommendations [19]. For instance, online app 'Chimae Check' which assists diagnosis of dementia and introduces management methods, forbids certain activities like drinking while promotes healthy lifestyles such as physical exercise or fish diet. They have not looked at characteristics of the person who is actually performing those lifestyle changes. Second, of course there are also numerous studies on the psychology of the older adults and its impact on cognitive health as well as physical health [20]. Yet those researches on psychology have examined only those older adults before suffering from dementia. The older adults with dementia are implicitly treated as having similar kinds of psychology. This pilot study opens a new field of research on the personality of the older adults with dementia.

Table 2. Factors Affecting Dementia from Newspapers and FGIs

Source / Factors	Newspapers	FGIs
Personal	Habit of taking notes Objects of memories Habit of Physical Exercise (Dance, Walking) Game/Hobby (Baduk, Knitting)	Personality(AeSal) : - Self-management capability - Positive attitude - Stress control - Selfishness Habit of Exercise

Social	Day care Center program Village community Education program	Next of Kin Companion Outing / Taking a walk

3.3 Personality as a type of data

Experts agree that personality of the older adults has yet been studied scientifically, which means it throws challenges as a new type of data. Once personality of the older adults is acknowledged as a dementia-affecting factor, then the question of measurement immediately follows. In other words, collecting good quality data on personality become a scientific challenge. 3 aspects can be discussed.

First, it would a daunting task to get a reliable data from the older adults with dementia because of obvious communication difficulties. One could devise questionnaires which help reveal personality of the older adults. Yet, it is reasonable to doubt whether the interviewees fully understand the meaning of questions and answer accordingly. The selection of question or the phrasing of question is something to be carefully made in order to gain good quality data. Citizen science approach would be critical in such research endeavors.

Second, other methods for assuring data quality need to be developed. It might be an idea that on behalf of the older adults, caregivers or social workers who are familiar with them may respond to the questionnaires. They might be in a better position to measure the personality of the cared. The conventional statistical approaches such as statistical modeling of systemic error are also area which can contribute to gain good quality data on personality.

Finally the search for other types of data explaining personality is recommendable. In digital world, various types of data such as text, image, signal, etc. are available and utilizable at very low cost. Profiling of individuals is an everyday business practice in data economy [17]. Measuring personality of the older adults could tap on the power of data economy utilizing various types of personal data.

4. Conclusions

This pilot study examined the contribution of citizen science approach to identifying factors influencing the progress of cognitive health of the older adults through newspaper analysis and FGIs of field workers at a Day Care Center. Two questions were put forward; whether new factors are drawn from citizen knowledge pool; whether they represent new type of data. Personality of the older adults with dementia are noted as a promising new dementia affecting factor which requires further study. The data on personality also present a new challenge of measurement. The relationship between personality or psychology of the older adults and the risk of getting dementia has been a popular research field for a long time, yet the impact of personality on the progress of dementia has not been looked at as deeply. Because of the obvious communication difficulties, new types of data, new ways of data collection and measurement is required before serious scientific enquiry into the newly identified subject.

Even though it was a pilot scale project, citizen science approach proves to be beneficial in tackling areas like older adults care where citizens, practitioners, and non-professionals has knowledge and capability more pertinent than experts. They do have knowledge and capability which may be embedded in tacit form yet to be transformed to explicit one. The data economy and ‘datification’ technologies would help citizen science approach to mine and reveal the knowledge embodied in citizen. In fact citizen science approach has been in full operation at the online platform ‘PatientsLikeme’, where citizens, patients, doctors and nurses exchange, interact and learn from each other [21]. Larger scale citizen science project on dementia-affecting factors should be the next research step.

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