Opinion

UNMET NEED IN GERIATRICS– PATIENT VOICE

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Abstract
Rapid advancements in patient-care facilities are steadily increasing the global elderly population. Despite this demographic shift, the elderly population continues to be poorly represented in research studies. This report explores the potential of survey-based research as a valuable tool to gather missing data and ensure inclusivity of the elderly population, especially in the context of rare rheumatic diseases.

Keywords: ageing; COVID-19; geriatrics; research; surveys; questionnaires.

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Ageing can be defined as the progressive deterioration of biological functions necessary for survival and fertility [1]. As individuals age, they become more prone to developing multiple complex conditions simultaneously. The elderly population is typically defined as individuals aged 65 years or older [2]. Enhanced healthcare promotes longevity. As a result, more people are approaching the “elderly” benchmark. This is termed as population ageing.

Growing burden of elderly population calls for focused geriatric care. However, this population is often underrepresented in clinical trials and observational studies across various medical fields, particularly in the context of rare rheumatic diseases [3–9]. This underrepresentation poses significant risks, as the elderly population differs from younger individuals in several aspects such as pharmacodynamics, pharmacokinetics, co-morbidities, polypharmacy, physical performance,
cognitive impairment, and fragmented social support systems [3, 10]. It is crucial to include diverse populations, taking into account the pharmacodynamic and pharmacokinetic interactions specific to elderly individuals with coexisting conditions, in order to generalize study results effectively [11, 12, 13].

A significant impediment to the inclusion of the elderly in research studies is cognitive impairment. Lacking judgement capacity to consent to and participate in research and recall bias may compel the investigators to exclude them from research studies [14]. The exclusion criteria to identify participants with cognitive impairment as ineligible for participation commonly includes applying cognitive screening tests like the Mini-Mental State Examination (MMSE) [15,16,17] among others.

The presence of multiple coexisting conditions leading to poor health status often acts as a barrier for elderly individuals to participate in surveys. Additionally, the lack of patient support groups and disparities in health strategies and access to basic amenities in low and middle-income countries contribute to the disparity in participation rates [26]. Other factors such as audio-visual impairment, difficulties in understanding survey materials, transportation issues, and technological illiteracy can also hinder participation [19]. However, it is anticipated that in the forthcoming years, the prevalence of technological illiteracy will significantly decrease. Tapping into the potential of survey based studies may allow greater access to the elderly, for subjects where patient voice may generate valuable data such as ePROs. [20]. Survey-based research offers a cost-effective and convenient method for recruiting and retaining participants, as it allows patients to participate from the comfort of their surroundings and at their own pace. Conducting and analyzing survey-based research studies is relatively easier, and they enable the collection of valuable data on rare diseases from underrepresented populations [21–23]. Additionally, survey-based research plays a crucial role in capturing the voices of patients, engaging them as active partners in health research, and providing valuable insights to enhance patient care [24]. In recent years, there has been a significant increase in social media usage by the elderly population. Internet use significantly rose from 60.2% in 2011 to 66.4% in 2016 among the elderly population in the United States [25]. A study conducted on 3141 elderly individuals demonstrated a positive correlation between social participation, internet use and improved health status. [26] To increase engagement, surveys can be disseminated through popular social media platforms such as Twitter and Facebook, even during global emergencies such as pandemics and wars. Direct outreach to patient-support groups via social media can also be an effective strategy. Preliminary data from the ongoing COVID-19 Vaccination in Autoimmune Diseases (COVAD) study, a global patient self-reported electronic survey, indicates that a significant proportion of respondents were elderly individuals, predominantly from the United States of America and the United Kingdom [27, 28]. The COVAD study was designed to gather data on the short-term and long-term efficacy of COVID-19 vaccines in autoimmune rheumatic disease patients, with a focus on the myositis population. Well-designed surveys, such as NHANES (National Health and Nutrition Examination Survey), have proven to be invaluable tools for collecting population-level data both before and after the pandemic. These surveys play a crucial role in providing comprehensive insights into various health-related aspects, including demographics, health behaviors, and clinical measurements. By capturing data from a representative sample of the population, surveys like NHANES enable researchers and policymakers to understand trends, identify health disparities, and evaluate the impact of interventions.

By leveraging the advantages of survey-based research and employing effective dissemination strategies, valuable insights can be gathered, particularly from underrepresented populations, to contribute to the understanding and improvement of patient care.

The literature has extensively documented validated patient-reported outcome measures [29]. However, there is ongoing debate regarding their effectiveness in fully capturing the range of outcomes in the elderly population [10].

Survey-based studies indeed come with their own set of limitations, which can impact the validity and reliability of their findings. Some of these limitations include:

- Self-reporting bias: Participants may provide inaccurate or biased information about themselves or their experiences, influenced by social desirability or memory lapses.
- Non-reporting bias: Some participants may choose not to disclose certain information, leading to incomplete or skewed data.
- Sampling bias: The survey sample might not be fully representative of the target population, introducing potential generalizability issues.
- Measurement errors: Errors can occur in the way questions are formulated, leading to misunderstandings or misinterpretations by respondents.
- Limited depth of information: Surveys may not capture the full complexity of certain
phenomena or allow for in-depth exploration of individual responses.

- Response rate bias: Low response rates can lead to a lack of diversity in the sample and compromise the survey’s reliability.
- Recall bias: Participants may have difficulty accurately recalling past events, leading to biased responses.
- Social desirability bias: Respondents might alter their answers to appear more socially acceptable or desirable.

Despite these limitations, survey-based studies remain valuable tools for collecting data on a large scale and understanding trends and patterns within a given population. Researchers should acknowledge and address these limitations appropriately to enhance the credibility and robustness of their findings.

Nevertheless, with the emergence of the internet and the utilization of social media and survey-based research, there is potential for better inclusivity of underrepresented populations, including the elderly, in research on rare rheumatic diseases. This has significant implications for future medical and population research endeavors. By leveraging these technological advancements, researchers can strive for more comprehensive and representative data, leading to a better understanding of the outcomes and needs of the elderly population in the context of rare rheumatic diseases.

CONFLICT OF INTEREST
The author declares no conflicts of interest regarding the publication of this article.

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