

Research advance in self-advocacy in elderly patients

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Abstract: Elderly patients have become the main focus of China's elderly care industry, and solving the various needs of elderly patients is currently a key issue in China's nursing industry and even the whole society. Improving the level of self-advocacy of elderly patients can enable them to independently collect disease-related information, obtain social support, and then take the initiative to carry out various medical treatment, cooperation and care, and effectively manage their own diseases. At present, there are many foreign studies on the self-advocacy of elderly patients and some progress has been made, but China is still in its infancy in this regard. Therefore, this article will review the influencing factors, evaluation tools and interventions of self-advocacy in elderly patients, in order to provide a basis for the development of self-advocacy in elderly patients.

Keywords: Self-advocacy; Elderly patients; Research advance; Review

1. Introduction

According to the economic data released by the National Bureau of Statistics for the whole year of 2022, at the end of 2022, the national population aged 60 and above will be 280 million, accounting for 19.8% of the national population, of which about 210 million people aged 65 and above, accounting for 14.9% of the national population. Compared with the latest 2021 national census statistics^[1], the elderly population over 65 years old has increased from 14.2% to 14.9%, entering a new stage of aging society. In the first half of the 21st century, the aging of the Chinese population has developed rapidly, and according to the international standard of 60 years old for the elderly, China will reach the aging social standard of the proportion of the elderly population in the total population as soon as 2040^[2]. The elderly population is growing, and as individuals with reduced physiological functions, the number of elderly patients will also increase significantly. With the rapid increase in the elderly population, aging has become a global public health problem^[3]. The study^[4] predicts that the number of disabled elderly people in China will reach 61.68 million in 2030. The growth of the elderly population and the disabled elderly population poses a major challenge to the health and social care system, so how to maintain the elderly, especially the elderly, healthy and independent living is a topic of great social value.

2. Concepts

Self-advocacy^[5-6] refers to the ability of patients to actively learn to obtain relevant information about the disease through active learning, the ability to actively put forward their own needs and reasonable requirements, and the ability to actively prevent or stop violations of their own rights and interests when they learn of their own illness and manage their own body after learning of their illness^[7]. The right to self-advocacy was first proposed by Brashers et al.^[8] at the 1992 Annual Psychological Conference, which included acquiring knowledge of related diseases, enhancing confidence in facing diseases, and actively screening information. In 1999, Walsh et al.^[9] argued that in cancer populations, self-advocacy refers specifically to confidence and choice to defend one's own interests. In 2013, Hagan et al.^[10] redefined self-advocacy as the ability of individuals to put their needs and wishes first in the face of illness. Common themes of these concepts of self-advocacy include access to information, asking questions, communicating with health professionals, and asserting one's own individual rights. Studies^[11] have shown that enhancing self-advocacy in older patients can enhance their ability to collect disease information, obtain external support, and further improve patients' ability to manage their own diseases^[12]. Self-advocacy has been identified as a key component of improved health outcomes, and patients' ability to proactively acquire knowledge about their health, society, and personal needs not only enables

patients to become active health care providers, but also enables individuals to promote self-worth and identity recognition in ensuring their own health and care [13].

3. Factors influencing self-advocacy

3.1 General demographic data

The study concluded that gender, age, education level, economic ability, region, and disease severity were closely related to self-advocacy. In terms of gender, women have stronger self-advocacy, and Kolmes et al. [14] found that women scored higher than men on the self-advocacy scale. Lindsay et al. [15] found that men have weaker self-advocacy and that men need more non-therapeutic help from health care professionals in clinical care than women. Sharma et al. [16] research believes that the reason for women's strong self-advocacy may be that women are stronger in communication and can ask questions in time. In terms of factors such as age, education level, and economic ability, Wiltshire et al. [17] pointed out that people with younger age, high education level and strong economic ability are more likely to realize self-advocacy. Younger, more educated people are more likely to access and understand relevant information, while the latter have more support resources. In terms of region-related factors, Novinger et al. [18] conducted a survey in the elderly population, and the results showed that the self-advocacy ability of the elderly in urban areas is generally higher than that in rural areas, and the reasons may be related to the higher education level, higher economic level, more social resources, and richer information channels of the elderly in urban areas. In addition, Cleve et al. [19] have shown that white people are more able to put forward their own needs and achieve self-advocacy. In terms of disease severity, Hagan et al. [20] found that the severity of the patient's condition is positively correlated with self-advocacy ability, which may be due to the fact that when the patient's condition is urgent and serious, the communication with medical personnel is increased, which can indirectly increase the knowledge of the disease. Wang Nannan [21] et al. conducted a survey in female cancer patients, and the results showed that the education level was related to self-advocacy, and patients with high education level had higher self-advocacy ability. However, the reasons for the difference between age, economic level, disease severity and self-advocacy ability may be the difference between domestic and foreign medical systems, differences in medical costs, family forms, differences in domestic regions, and limited samples.

3.2 Mental state

Bishop et al. [22] believe that negative psychological states such as anxiety and depression affect self-advocacy ability by reducing patients' decision-making ability. Similarly, Thomas et al. [23] have shown that anxiety and depression reduce patients' self-advocacy by reducing their self-initiative and motivation. In addition, the study [24-25] found that positive psychological factors such as sufficient happiness, high self-efficacy, and self-esteem had a positive impact on self-advocacy ability through the study of positive psychological states. Tilley et al. [24] found that patients with high happiness in the intellectual disability group also had stronger self-advocacy. In the study of Michael et al. [25], hearing impairment and normal people analyzed their self-efficacy, self-esteem level and self-advocacy, and found that people with high self-efficacy and high self-esteem had higher self-advocacy ability, which may be related to the fact that people with intellectual disabilities or hearing impairments have more limited access to information than ordinary people. Hagan's [26] study of female cancer patients suggests that the level of self-advocacy increases with the sense of benefit. In summary, the level of self-advocacy was positively correlated with positive psychological factors and negatively correlated with negative psychological factors.

3.3 Social support

A Korean study of the elderly population in the community found that patients with adequate social support were able to have higher decision-making ability in the face of disease [27]. Another study [28] also showed that patients can draw strength from the social support system to face the disease with a positive attitude when they are ill, greatly improving treatment adherence and increasing medical participation. The study [29] clearly pointed out that social support has a close impact on self-advocacy, and the improvement of social support system can further enhance patients' self-advocacy ability by enhancing patients' social relationships and expanding information access channels.

4. Self-advocacy capacity assessment tool

4.1 Seniors Empowerment and Advocacy in Patient Safety. SEAPS

This scale was developed in 2007 by Elder et al.^[30] to measure the ability of elderly patients to advocate for safety in the hospital during outpatient visits, and the scale consists of four subscales, namely outcome effectiveness (OE), attitude (ATT), self-efficacy (SE) and behavior (BEH). ATT's Cronbach's α was 0.74, BEH was 0.79, and OE and SE were 0.91. Analysis of variance showed no difference in subscale scores among patients of different ethnicities, education levels, or frequency of visits ($P > 0.05$). Women scored higher on the overall score of all subscales, with significantly higher scores on ATT and SE subscales in particular ($P < 0.01$). The scale was administered to 200 older adults with 143 valid questionnaires. The accuracy range of the subscale was 4.6 to 6.0%, and the reliability and validity were good.

4.2 Patient Self-Advocacy Scale. PSAS

The PSAS scale was developed in 1992 by Brashers et al.^[31] to measure patients' self-advocacy in public health care, by adjusting the existing 12 patient self-claim scales, which include the following three dimensions: (1) increased disease education; (2) increase confidence in doctors; (3) There is a possibility of intentional non-compliance with prescribed treatment, and the internal consistency of the overall score of the scale is good ($\alpha = 0.77$). education subscale ($\alpha = 0.76$). Confidence subscale ($\alpha = 0.77$) and note non-adherence to the subscale ($\alpha = 0.70$). Entries are scored by 5 points of Likert, from "strongly agree" to "strongly disagree" with a score of 1~5, for a total score of 12~60 points. The higher the score, the higher the level of patient self-advocacy. The PSAS scale, originally developed for AIDS patients, tested for reliability and validity in 174 HIV/AIDS patients, with a Cronbach's α coefficient of 0.78. Adjusted by Carol et al.^[27] in 2008, the scale was modified to apply to cancer survivors. The new PSAS scale was validated in 120 cancer patients with a Cronbach's α coefficient of 0.745, which is comparable to the original scale Cronbach's α coefficient of 0.78, all of which have good reliability and validity.

4.3 Self-Advocacy Scale. SAS

Constructed by Hawley et al.^[32] in 2016, the scale includes 3 dimensions of self-care level, organizational ability, and communication, a total of 8 items, and a 4-level Likert rating scale (1 = not confident, 4 = very confident) to measure the current confidence of patients with head injury in self-advocacy behavior, the higher the score, the higher the self-advocacy efficacy, the total score range is 8 ~ 32 points. In 162 patients with brain injury, the scale Cronbach's α coefficient was 0.97, the calibration standard association validity was 0.82, and the reliability and validity were good.

4.4 Personal Advocacy Activity Scale. PAAS

Constructed by Hawley et al.^[32] in 2016, it is a reliable and valid 12-item individual advocacy behavior self-rating scale. All 12 items deal with individual self-advocacy. Participants need to indicate the frequency of individual advocacy behavior in the past 6 weeks in choice 1 (no at all), choice 2 (1-4 times) or choice 3 (≥ 5 times), with a total score of 12~36 points, the higher the score, the more personal advocacy behavior. The PAAS scale is constructed by adjusting the existing 12 patient self-advocacy scales (AAS), constructed by Malec et al.^[33] in 2010, and includes 3 dimensions: (1) disease education; (2) medical confidence; (3) Intentional non-compliance, the scale was tested for reliability and validity in 332 patients, and the reliability coefficient of the scale items was 0.97.

4.5 Female Self-Advocacy in Cancer Survivor ship. FSACS

The FSACS scale, compiled by Hagan et al.^[34] equal to 2016, is a scale that assesses how female cancer survivors advocate for their needs and priorities when facing challenges, containing 20 items, using a 6-point scale Likert scale, a self-assessment scale ranging from 0 (strongly disagreed) ~ 6 (strongly agreed), the higher the score, the greater the patient's ability to advocate. The scale includes three dimensions: (1) Information competence reflects women's ability to find reliable information and apply it to themselves. (2) Support ability refers to a woman's ability to balance the needs of herself and others, as well as the ability to gain strength through relationships. (3) Health care competency refers to

a woman's ability to build a good relationship with a health care team. In 317 female cancer patients, the internal consistency of FSACS was strong ($\alpha = 0.92$), and the Cronbach's α in 3 dimensions was 0.79~0.85, and the correlation coefficient was $r = 0.85\sim 0.97$.

5. Interventions to improve self-advocacy in older patients

5.1 Knowledge education

5.1.1 3RS Health Self-Advocacy Training

The 3Rs Health Knowledge Course^[35] is designed specifically for people with intellectual disabilities and language skills impairments to provide a brief introduction to the human body, covering important body organs and biological systems. The pedagogical approach is based on behavioral universal design of elements of learning principles and techniques, emphasizing the need for pedagogical approaches to adapt to learners' learning styles, breaking down complex concepts and tasks into smaller units, providing many examples to facilitate learning and engaging learners in interactive activities. Participants also needed to take time to write their own health diaries, in which they recorded important information about themselves to share with health care professionals. The 3Rs Health Self-Advocacy course consists of two parts, Health Knowledge and Health Rights. Feldman et al.^[36] randomly divided 20 patients with intellectual disabilities who had received health knowledge training into a training group and a control group, selected 11 additional patients who had not received any health knowledge training, randomly added to the training group or control group, and finally 18 participants in the health knowledge training group and 13 in the control group. Pre-treatment, post-treatment and follow-up trials were conducted in both groups. Research shows that people with mild and moderate intellectual disabilities can learn self-advocacy skills through a combination of slides, interactive videos, and group training in the form of games. The training group performed significantly better than the control group in test questionnaires and surveys. However, the sample size of this study is small and the research population is special, and it can be further adjusted to adapt to a variety of patients and conduct a large number of this study in the future.

5.1.2 Recreational education

The Educational and Entertainment Decision Assistance Model (EDAM) is a help decision aid that combines a well-crafted storyline with actual medical information, with the goal of helping participants make relevant decisions through a situational interface like a TV series. It consists of two main parts: interactive learning and didactic episodes. Volk et al.^[37] applied it to prostate cancer patients, and the experimental group used sitcom to learn, including prostate cancer facts, risk factors, screening tests, treatment options, complications, and review of the disease. The control group read the above to the patient using an audio booklet. The results of the study showed that patients who received entertainment sitcoms scored higher on the Self-Advocacy Proficiency Scale than those who received audio pamphlets. Hoffman et al.^[38] used the method on 89 patients with rectal cancer, randomly divided them into two groups, the experimental group patients watched a patient decision aid video containing relevant information about colo-rectal cancer screening, presented in the form of entertainment and education, and the control group patients watched a video about hypertension with detailed information about hypertension disease. After the viewing, participants met with their physicians and completed follow-up questionnaires to assess their level of knowledge, conflicting decision-making, self-advocacy, and intent to undergo rectal cancer screening. The results showed that the willingness of participants in the experimental group to screen for rectal cancer was significantly different from that of the control group. More patients in the experimental group were willing to be screened, had more relevant knowledge, and scored higher on self-advocacy. Both studies show that entertainment education can improve the level of self-advocacy of patients, and in the future, Chinese scholars can adjust the method to adapt to domestic elderly patients to improve the self-advocacy level of domestic elderly patients.

5.2 Cultivating Individual self-advocacy

Hawley et al.^[39] applied the self-advocacy program to 12 patients with brain injury, conducted four times over 6 weeks, taught in the form of group seminars and compiled into an educational handbook for individual self-advocacy, emphasizing the beliefs, knowledge, and skills necessary for self-development and self-advocacy. The study group conducted an interactive meeting, while the control group issued only one handbook during which researchers could be asked questions. SAS scores were performed before and after the intervention, and SAS scores increased in both groups after the intervention, with

the baseline SAS score in the control group being higher than that in the study group, but the post-intervention score was lower than in the intervention group, but the difference was not statistically significant. The PAAS scores in the study group were higher than those in the control group. It shows that the self-advocacy program can significantly improve the self-advocacy ability of individuals to a certain extent. In the future, Chinese scholars can further refine the manual and teaching content to adapt to elderly patients and related diseases.

5.3 Peer support

Susan et al. [40] selected 428 people with mental illness as study subjects and randomly divided them into 212 in the control group and 216 in the intervention group for a three-year bridging course, an 8-week peer-guided education program designed to enhance the rights and promote the rehabilitation of adults with mental disabilities. Topics covered include self-advocacy, communication and problem-solving skills, social support, psychiatric diagnosis, medication and mental health therapy, and crisis planning. The course size is a group of 12~15 people, and the course and course materials are free. Courses are conducted through lectures, group exercises, personal experience sharing and group discussions. During the duration of the program, the control group received usual services, i.e., the same treatment as the intervention group except for the course. Routine services include medication management, case management, and individualized treatment. Six months after the intervention, 18 patient self-advocacy scales (PSAS) were used for scoring. Compared to the control group, patients in the intervention group had significant improvements in overall empowerment and self-esteem over time, and significantly increased self-advocacy and self-confidence. Illustrating that bridge courses can enhance patients' self-advocacy and have a significant role in overall patient empowerment.

6. Conclusion

As an effective way to improve the self-care ability and self-improvement of elderly patients, self-advocacy can further protect the rights and interests of elderly patients. At present, there are many foreign studies on self-advocacy, but the intervention is only carried out in a single center and a single type of patient, such as mental patients and intellectual disabilities, and other common diseases such as diabetes and hypertension are not targeted. In addition, inconsistent assessment tools may lead to different results evaluation, and in China is still in its infancy, domestic and foreign cultural differences, foreign interventions need to be further adjusted to suit Chinese patients, the future can be on the elderly patients' self-advocacy influencing factors and intervention design can be further improved, in order to provide more convenient and self-help care for elderly patients in China in the future.

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