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Caregiving risk perception characteristics and associated factors among informal caregivers of functionally dependent elderly individuals at home: a qualitative study

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Abstract

Background This study explored risk perception characteristics and influencing factors among informal caregivers of functionally dependent elderly individuals at home, aiming to improve caregivers' caregiving risk perception and coping abilities and ultimately enhance the quality of life for these individuals.

Methods We used purposive sampling to select 22 informal caregivers from a community in Zhengzhou City, Henan Province, China, between March and September 2023 and conducted face-to-face semi-structured in-depth interviews. The data were analyzed using Colaizzi's seven-step analysis method.

Results We extracted two themes, caregiving risk perception characteristics and caregiving risk perception associated factors, and eight sub-themes, perceived risk possibility, perceived risk anticipation, perceived severity of consequences, past caregiving experiences, health literacy, psychological status, caregiving burden, and family social support.

Conclusion There were differences in how informal caregivers perceived the risks associated with caring for functionally dependent elderly individuals at home, which various factors could influence. It was essential to provide training that covered the knowledge and skills needed for caregiving, improve caregivers' awareness of safety risks, and establish a correct perception of caregiving risks. The government must construct and refine a comprehensive framework for caregiver respite services. Simultaneously, healthcare professionals should proactively undertake health education endeavors to augment the recognition of care safety risks among informal caregivers, thereby cultivating an accurate awareness of care risk perception.

Keywords Home-based care, Elderly, Functional dependence, Informal caregivers, Caregiving safety, Risk perception, Influencing factors, Qualitative study

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Background

China's seventh national population census surveyed the population's quantity, structure, distribution, and other aspects. The results revealed that China is facing a severe issue of population aging, with approximately 260 million people aged 60 and above [1]. This elderly population was mainly characterized by advanced age, living in empty-nest households, and having functional or semi-functional disabilities. Functional disability refers to the partial or complete loss of specific physical functions, including the ability to perform activities of daily living, cognitive functions, and communication skills. This loss can be attributed to aging, illness, or disability, resulting in restrictions or the inability to perform standard activities [2]. China has one of the largest populations of functionally dependent elderly individuals in the world. As of the end of 2018, there were 44 million functionally dependent elderly individuals in China, expected to rise to over 60 million by 2030 and over 90 million by 2050 [3, 4].

Due to physiological decline, bodily ailments, and mental disorders, functionally dependent elderly individuals often experience significant limitations in their ability to perform daily activities. Addressing their long-term care needs is crucial for establishing a comprehensive basic care service system [5, 6]. In China's established "90-7-3" elderly care pattern, 90% of elderly individuals preferred home-based care, 7% preferred community-based care, and 3% preferred institutional care, with home-based care being the predominant and most widespread model [7]. Informal caregivers, such as spouses, children, relatives, and friends, play the most direct role in caring for functionally dependent elderly individuals at home [8, 9]. However, they face challenges due to limited educational and training resources, insufficient social recognition and support, an imperfect social welfare and long-term care insurance system, a lack of respite services, and inadequate legal protection [10]. These barriers hinder their ability to acquire the necessary knowledge and skills, affecting their ability to identify and respond to care risks, which can lead to various accidents, such as pressure ulcers, falls, malnutrition, infections, and accidental catheter removal, which severely impact the quality of life of elderly [11–13].

In the health field, risk perception refers to individuals' cognitive understanding and awareness of potential dangers, threats, or uncertainties related to health, including sensitivity and consciousness regarding various risk factors that may affect health. Fischhoff [14] first proposed risk perception theory, becoming the most commonly used method in risk assessment research. The theory included three dimensions: the uncertainty of risk occurrence, the severity of consequences, and societal and personal exposure. The uncertainty of risk occurrence refers to assessing the likelihood of a specific risk occurring within a certain period. The severity of consequences involves the evaluation of the outcomes of risk, including its impacts on health, the economy, society, and psychology. Societal and personal exposure pertains to the degree to which individuals and society are exposed to risks, including the opportunities for individuals to encounter specific risks in their daily lives and the distribution and impact of risks at the societal level [15]. Numerous studies [16–18]have demonstrated that accurate risk perception and appropriate management can alter elderly individuals' maladaptive behaviors, improve their health status, and prevent relapses. Therefore, understanding informal caregivers' perception of caregiving risks and the influencing factors is crucial. However, current research has mainly focused on caregivers' caregiving behaviors, caregiving burden, caregiving experiences, and needs [19–22], with less attention given to the perception and characteristics of safety risks among informal caregivers of functionally dependent elderly individuals receiving home-based care. This study adopted a phenomenological research approach to delve deeply into risk perception characteristics and influencing factors among informal caregivers of functionally dependent elderly individuals at home. The aim was to provide a reference for developing intervention programs targeting the risk perception and coping strategies of informal caregivers.

Materials and methods

Study objectives

The specific objectives of this study are as follows: (1) To explore the characteristics of care risk perception among informal caregivers of homebound elderly individuals with disabilities. (2) To investigate the factors influencing the perception of care risks among informal caregivers of homebound elderly individuals with disabilities and to understand their impact on the informal caregivers and the disabled elderly. (3) To propose potential solutions and intervention measures for enhancing the ability of informal caregivers to perceive care risks for homebound elderly individuals with disabilities, thereby improving the quality of life of these elderly individuals.

Research design

This study was undertaken as a phenomenological analysis of qualitative research to explore the characteristics of care risk perception and related factors among informal caregivers of homebound elderly individuals with disabilities. This method is dedicated to investigating how individuals make sense of their life experiences and can be used to articulate participants' personal experiences and understandings in specific life circumstances [23]. Researchers must identify how participants comprehend

Table 1 Characteristics of Informal caregivers

Characteristics	Number (%)	Characteristics	Number (%)
Gender		Care Duration(month)	
Male	7 (31.8)	1–5	5(22.7)
Female	15(68.2)	6–10	7(31.8)
Educational Background		11–15	8(36.4)
Primary school	5(22.7)	16–20	2(9.1)
Middle school	5(22.7)	Age(years)	
High school	3(13.6)	30–40	6(27.4)
Junior college	4(18.2)	41–50	7(31.8)
Undergraduate	2(9.1)	51–60	7(31.8)
Master	3(13.7)	61–70	1(4.5)
		71–80	1(4.5)

Table 2 Characteristics of functionally dependent Elderly individuals

Characteristics	Number (%)	Characteristics	Number (%)
Gender		Disability Level	
Male	11(50)	1	2(9.1)
Female	11(50)	2	4(18.2)
Age(years)		3	7(31.8)
51–60	2(9.1)	4	6(27.4)
61–70	10(45.4)	5	3(13.5)
71–80	8(36.4)		
≥81	2(9.1)		

Note: Disability Level: Level 1 is mild disability, Level 2 is moderate disability, Level 3 is severe disability level I, Level 4 is severe disability level II, and Level 5 is severe disability level III

their life experiences within a particular cultural context. This study strictly followed the Consolidated criteria for reporting qualitative research (COREQ) guidelines (Supplementary Material S1) [24].

Interview subjects

Using purposive sampling, two researchers (ZHQ and ZQH) selected informal caregivers of functionally dependent elderly individuals in a community in Zhengzhou City, Henan Province, China, as study subjects from March 2023 to September 2023.

Inclusion criteria included: (1) The care recipient must be functionally dependent elderly individuals aged 60 or above, with disability levels assessed according to the "Assessment Standards for Disability Levels in Long-term Care (Trial)" jointly issued by the National Medical Insurance Administration and the Ministry of Civil Affairs [25], with a score of ≥Level I; (2) Caregivers must be direct relatives and primary caregivers of the patients aged 18 or above and not receive any labor compensation; (3) Informed and voluntary participation.

Exclusion criteria included: (1) caregivers with a history of mental illness or cognitive impairment; (2) caregivers who could not communicate effectively. The Zhengzhou University ethics committee in China approved all study procedures (approval number: ZZUIRB2021-78), and all patients provided written consent. We conducted interviews until no new themes emerged and new categories ceased to appear during data organization and analysis. Twenty-two informal caregivers were interviewed, including seven males and fifteen females, with an average age of (48.50±10.20) years. Characteristics of informal caregivers and functionally dependent elderly individuals are detailed in Tables 1 and 2.

Development of interview guide

Guided by the multidimensional model of risk perception theory, which encompasses the uncertainty of risk occurrence, severity of consequences, and societal and personal exposure [26–28], and informed by relevant literature, risk perception theory, and pre-interviews with two informal caregivers of functionally dependent elderly individuals, we formulated the interview guide as follows: (1) What relevant caregiving knowledge and skills do you possess, and how did you acquire them? (2) What are your main tasks when caring for functionally dependent elderly individuals? Have there been any caregiving accidents? (3) What do you think might cause caregiving risks and accidents? (4) What adverse consequences do you think these caregiving risks and accidents may have on the elderly and yourself? (5) How do you anticipate when caregiving risks and accidents are about to occur? (6) How do you feel when caregiving accidents occur? (7) What methods do you employ to deal with caregiving risks? (8) What difficulties do you encounter in preventing and addressing caregiving accidents? (9) What factors do you think may lead to the occurrence of caregiving risks and accidents?

Data collection

Utilizing a phenomenological research approach, two researchers (ZHQ and ZQH) conducted one-on-one semi-structured interviews to collect data, prioritizing the convenience of the participants regarding the timing and location of these interviews. Before initiating the interviews, ZHQ and ZQH recommended that community health service staff facilitate the establishment of rapport between the interviewer and the interviewees. The researchers(ZHQ and ZQH) explained the purpose and significance of the interviews to the participants, ensuring their anonymity by assigning participant numbers instead of using names. The participants signed informed consent forms, and the interviews proceeded only with their agreement, with their consent recorded. Throughout the interviews, we(ZHQ and ZQH) employed techniques such as questioning, active listening, responding, probing, and repeating to alleviate potential anxiety among the participants. We(ZHQ

and ZQH) also noted non-verbal cues, including facial expressions, gestures, and emotional changes. Participants were encouraged to express their genuine feelings and opinions freely, and we(ZHQ and ZQH) refrained from using leading questions or suggestions to prevent bias in the responses, thereby avoiding the Hawthorne effect. If we(ZHQ and ZQH) noticed significant emotional fluctuations in the participants, we adjusted the direction of the conversation or paused it accordingly. We(ZHQ and ZQH) promptly verified the answers provided by the participants to ensure the reliability of the data. Additionally, with the caregivers' consent, we(ZHQ and ZQH) conducted on-site observations of the caregiving environment and skills following the interviews, meticulously documenting the results. We concluded the interviews upon reaching data saturation, with no new themes emerging. We(ZHQ and ZQH) strictly controlled the duration of each interview within 0.5 to 1 h and promptly documented relevant data afterward [29].

Data organization and analysis

The two researchers (ZHQ and ZQH) transcribed the interview recordings into text within 24 h of the interview's conclusion and then manually coded, categorized, and summarized the data using Microsoft Word and Excel. In this study, Colaizzi's 7-step analysis method was used to analyze the interview data: We carefully recorded and thoroughly read all the interview data; extracted statements that closely aligned with and were significant to the "perception of care risks"; induced and refined meanings from meaningful statements; sought common characteristics or concepts among these meanings to form themes, thematic clusters, and categories; wrote detailed and comprehensive descriptions without omissions; related the themes to the research phenomena and provided a complete narrative; and returned to the interviewee for verification when there was doubt [23]. During data analysis, we maintained an open mind and avoided personal values and preconceived notions as much as possible to prevent their impact on the results. Two researchers(ZHQ and ZQH) coded the data independently, and then we discussed the analysis results with the other researchers(XTY, WXX, QYM, ZSMY and LQF) to gather their opinions. Ultimately, the authenticity was verified through face-to-face or telephone conversations with the research subjects. Examples of the data analysis are presented in Table 3.

Rigor and reflexivity

In this study, Lincoln and Guba's criteria of credibility, transferability, dependability, and confirmability were utilized to ensure rigor [30]. The following strategies were implemented to achieve credible study findings: All researchers underwent specialized training in qualitative research, were familiar with the relevant content in this field, and mastered basic research methods and communication skills, establishing a good relationship of trust with the research subjects; two researchers (ZHQ and ZQH) conducted one-on-one semi-structured interviews to collect data; the other researchers(XTY, WXX, QYM, ZSMY and LQF) with extensive experience in qualitative research reviewed the transcribed materials and provided feedback; two researchers(ZHQ and ZHQ) involved in the interviews conducted independent analyses of the content and then shared their findings with the team members(XTY, WXX, QYM, ZSMY and LQF), soliciting their opinions; two researchers(ZHQ and ZHQ) verified the authenticity through face-to-face

Table 3 Examples of the data analysis

Data extract	Code	Sub-theme	Theme
1. I was always by her side. How could I have an accident?	Underestimate the possibility of safety risks	Perceived Risk Possibility	Characteristics of Caregiving Risk Perception
2. Whenever he moved at night, he made me stay awake all night; I was having a nervous breakdown.	Overestimate the possibility of risks		
3. When she started to breathe heavily, I knew it was because of excessive phlegm, so I suctioned it out to prevent choking.	The older adult's physiological condition	Perceived Risk Anticipation	
4. She had a urinary catheter and a gastric tube, but she kept pulling them out, causing bleeding everywhere. Now, whenever I was not by her bedside, I wore gloves to prevent her from pulling them out.	The older adult's behavior.		
5. When I saw him looking impatient and uncomfortable, I thought it might be related to his bowel or bladder, so I changed his diapers or turned him over for cleaning.	The older adult's facial expressions.		
6. People said that having pressure ulcers meant death was near, right?	Lead to severe consequences for the elderly	Perceived Severity of Consequences	
7. I was afraid he would break a bone. He was old, and I wondered how I could care for him if he broke a bone. I had developed many health problems due to taking care of him for a long time.	Increase caregiver's physical and mental burden and create economic pressure		

or telephone conversations with the informal caregivers; there was no communication between the informal caregivers. Regarding transferability, this study described in detail the inclusion criteria, exclusion criteria, and demographic characteristics involved. The researchers employed a triangulation method, which involved multiple researchers analyzing the data from different perspectives to ensure the dependability of the results. Confirmability was achieved through the researchers being aware of subjectivity by using member checking and peer review.

Results

Theme 1: characteristics of caregiving risk perception

Perceived risk possibility

Perceived risk possibility reflected caregivers' knowledge and skills about caregiving and the health status of the disabled older person. Interviews revealed that some caregivers were unthinkingly confident and underestimated the possibility of caring risks. Caregivers who tended to be optimistic and confident underestimated the possibility of risks, known as the "optimism bias, " which made people more willing to accept risks and believe that their decisions would lead to good outcomes while underestimating potential downside risks, a tendency that might have affected decision-making, behavioral choices, and the processing of information [31]. Some caregivers had the potential to underestimate the possibility of safety risks.

> *N11: "Although I had not cared for the elderly before, I had done housekeeping, and I could do all kinds of work, so it was no problem for me to take care of him. I had a low level of education, so I definitely couldn't learn."*

> *N4: "I was always by her side. How could I have an accident?"*

In addition, another proportion of carers might have been over-sensitive to caregiving risks and overestimated the possibility of risks occurring, which could have led to numerous physical and psychological maladjustments for the carer. Some carers reported often having poor sleep due to over-vigilance.

> *N16: "Whenever he moved at night, he made me stay awake all night; I was having a nervous breakdown."*

> *N18: "When she suddenly got dizzy, I was especially nervous and upset, afraid that her condition had worsened or that I had forgotten to give her medication, and sometimes I was overwhelmed."*

Perceived risk anticipation

Strong risk anticipation abilities enabled caregivers to identify potential dangers and take corresponding preventive measures. Some caregivers perceived uncertainty in risks based on the patient's physiological condition.

> *N8: "When she started to breathe heavily, I knew it was because of excessive phlegm, so I suctioned it out to prevent choking."*

> *N22: "She had difficulty swallowing, so I always made her food finely chopped to prevent choking."*

Others reduced the likelihood of risks by observing the older adult's behavior.

> *N6: "She had a urinary catheter and a gastric tube, but she kept pulling them out, causing bleeding everywhere. Now, whenever I was not by her bedside, I wore gloves to prevent her from pulling them out."*

Some caregivers judged risks by recognizing the older adult's facial expressions.

> *N14: "When I saw him looking impatient and uncomfortable, I thought it might be related to his bowel or bladder, so I changed his diapers or turned him over for cleaning."*

Perceived severity of consequences

Perceiving the severity of risks' consequences encouraged caregivers to provide proactive and effective care, reducing caregiving risks. Most caregivers knew that risks could lead to severe consequences for the elderly.

> *N20: "People said that having pressure ulcers meant death was near, right?"*

> *N15: "My mother had an open airway and produced much phlegm. I was afraid that if I did not suction the phlegm in time, she would suffocate."*

Additionally, most caregivers stated that adverse events not only increased their physical and mental burden but also created economic pressure.

> *N19: "I was afraid he would break a bone. He was old, and I wondered how I could care for him if he broke a bone. I had developed many health problems due to taking care of him for a long time."*

> *N21: "We did not have that much money at home. If*

my negligence worsened the situation, we could not afford the medical expenses."

Theme two: factors related to caregiving risk perception

Past caregiving experience

Caregivers usually gained experience from previous caregiving roles, which enhanced their comprehension of potential risks. Through the interviews, we discovered that each participant possessed distinct caregiving backgrounds that shaped their views and reactions to risks. Individuals with prior experience or significant consequences may have perceived caregiving risks as less prominent.

N2: "When I cared for my mother, she had no problems. I did not understand what accidents could happen. She got burned once; did that count?"

N12: "The first time I cared for my father, he would only call me when he felt uncomfortable. Sometimes, I could not detect if he was uncomfortable."

In contrast, caregivers with caregiving experience often had higher risk perceptions.

N5: "She could not control her pace and was prone to falls. Her legs were often bruised. Now, I did not let her walk around randomly and kept a close eye on her to prevent fractures."

N13: "When I was young, I took care of my father, who was bedridden for two years and developed pressure ulcers. It smelled terrible. Now, I was cautious when taking care of my spouse, worried that pressure ulcers might occur again, so I was very cautious."

Health literacy

Health literacy refers to the individual capability to obtain, process, and understand basic health-related information and make health decisions [32]. Limited health literacy could lead to poor health outcomes, affecting patient safety, quality of life, and access to healthcare information [33]. During the interviews, we found that about half of the caregivers could only provide essential daily care and needed more awareness of caregiving safety risks.

N10: "I did not understand much about the professional stuff. I cared for her daily needs and was unsure about the rest."

Caregivers with higher health literacy often learn and acquire caregiving knowledge through various channels.

N3: "Last year, my mom had a stroke and stayed in the hospital. Nurses checked her skin condition daily, reminded us to move her lower limbs, and turned her over regularly. Before she was discharged, I consulted nurses and doctors about what to pay attention to."

N9: "My mom had a cerebral hemorrhage and later contracted COVID-19. She was discharged with a stomach tube, urinary catheter, and an open airway. I bought an air mattress and suction machine online and asked a doctor online to teach me how to operate them."

Psychological status

According to the risk perception theory, an individual's psychological state could affect their level of risk perception [34]. A positive psychological state in long-term caregiving might have improved older adults' caregiving experience. When asked why they remained optimistic,

N1:" He raised me when I was young, and now I care for him when he is old. I am also setting an example for my children. When the day comes and I am bedridden, I hope my children will do the same."
N10: "Seeing him become more spirited each day made me happy, and he was not as troublesome as before."

However, some interviewees expressed negative emotions during long-term caregiving and dealing with risks, such as numbness, fatigue, and helplessness.

N7: "They said no filial sons by the sick bed. His consciousness was inferior now. He randomly grabbed the sheets and shouted, which was distressing and helpless."

Caregiving burden

Homebound functionally dependent elderly individuals require long-term care, especially those with higher levels of disability. Some caregivers expressed that their responsibilities and financial burdens associated with caregiving were significant, potentially diminishing their ability to perceive and respond to risks effectively.

N17: "I had been taking care of her for over a year at that point, and her health issues were multiplying—pressure sores, urinary and fecal incontinence.

At first, it had been manageable, but now I was exhausted every day. I was almost at wit's end. As long as I could ensure she eats and drinks well, I can't handle much else."

N20: "I quit my job to take care of my dad. I didn't have many financial resources. It was fine for a short time, but it's not sustainable in the long run. "

Family social support

Some caregivers often felt overwhelmed due to insufficient family social support, which triggered risks to some extent.

N3: "My children lived too far away. They returned a few times a year, and I had to care for him the rest of the time. "

N15: "I hoped community doctors and nurses could provide home services, but no such service was available. My mom couldn't take care of herself, and there was no one to take care of her if she went to the hospital. "

Elderly individuals with better family support had a lower probability of experiencing caregiving risks and accidents.

N13: "I was afraid my spouse might fall, so I installed handrails at home and bought fall prevention clothes and calcium supplements. My children came home every week to take my spouse for rehabilitation, and the recovery was pretty good. "

Some caregivers actively sought medical support to enhance their caregiving abilities.

N20: "I specifically hired a nurse to provide home care, which was labor-saving and safe. "

Discussion

Strengthening caregivers' knowledge and skills related to care safety to enhance risk perception

The results of this study indicated that 17 out of 22 caregivers lacked knowledge and skills related to care safety, consistent with previous research [35]. The health literacy and caregiving skills of caregivers determine the quality of their care and affect their ability to cope with care risks. Zhang Caihong [36] significantly improved caregivers' knowledge of pressure ulcer risks and reduced the incidence of pressure ulcers in patients by conducting health education on pressure ulcer risk assessment, prevention, and treatment. Healthcare professionals should train caregivers' knowledge and skills, build a scientific and systematic knowledge system of care risk prevention for the elderly with disabilities and their caregivers, and enhance caregivers' ability to assess and respond to care risks. Furthermore, this study found that caregivers with relatively good health literacy had a more comprehensive range of sources for care risk-related knowledge, primarily through nurse-patient communication and internet information. Good nurse-patient communication could improve patients' and caregivers' health literacy and promote shared decision-making between healthcare providers and patients [37]. Additionally, information acquisition could facilitate risk perception [38]. Healthcare professionals should strengthen communication between nurses and patients and, with the help of online platforms, provide caregivers with scientific and practical sources of health information. This study found that 6 out of 22 caregivers had limited caregiving experience, exhibiting negative coping strategies such as blind confidence, excessive worry, and ignorance without fear. Peer support refers to individuals with similar experiences using their own experiences to establish empathetic relationships and share experiences, offering each other suggestions and resource information to enhance coping abilities. Positive peer interactions could shift caregivers' focus from negative experiences to positive caregiving experiences, increasing their confidence in continuing to care and improving their quality of life [39]. Healthcare professionals should actively guide caregivers in correctly understanding caregiving risk perception. They should form peer support groups based on the characteristics and experiences of caregivers and the elderly with disabilities, regularly organize activities for these groups, encourage communication and interaction among members, share experiences in coping with caregiving risks, enhance caregivers' confidence in continuing to provide care, improve their quality of life, and reduce the occurrence of caregiving risks.

Paying attention to the psychological state of caregivers and promoting the traditional Chinese culture of filial piety

Emotions, as important explanatory factors for attitudes and risk perception, could influence caregivers' ability to cope with risks to some extent [40]. The results of this study showed that 13 out of 22 caregivers experience negative emotions such as numbness, fatigue, and helplessness, which increased the occurrence of care risks. Healthcare professionals should provide timely and effective psychological support and counseling, such as group psychological interventions and benefit finding, to improve caregivers' burden and reduce negative emotions [41, 42]. Additionally, this study revealed that 5 out of 22 caregivers held correct cultural values, identified

with the culture of filial piety, and could respond to care risks actively. A study [43] pointed out that caregivers' identification with filial piety and whether care is provided out of love directly affect the willingness to care. The diminishing of filial piety concepts could lead to a decrease in caregivers' desire to care, influencing the occurrence of unexpected care risks. Deeply influenced by traditional filial piety, the sense of responsibility significantly impacted the willingness of Chinese family caregivers to provide care. Most people actively assumed the responsibility of caring for the elderly. In contrast, a few others passively took on the role due to fear of public opinion and pressure from filial piety. However, those who passively assumed the caregiving role often found it challenging to continue in the long term, which could easily lead to increased risks in providing care [44]. The cultural norm of traditional filial piety typically advocated for a model of care confined within the family unit, often undervaluing the importance of professional healthcare services. Consequently, offspring may have resisted admitting their aging parents into formal care facilities due to societal perceptions, even when such facilities might have better catered to the health requirements of the elderly. In adherence to the principles of traditional filial piety, caregivers might have depended on conventional practices and personal experiences instead of adopting evidence-based nursing skills. This reliance on traditional approaches could have led to a need for more awareness regarding the risks involved in family-based care, potentially resulting in ineffective care provision or the introduction of hazards [45, 46]. Singapore has innovated its eldercare services by integrating Western professional nursing concepts with Eastern filial piety culture, developing a unique model of eldercare. The nation has implemented a "Family Caregiver Subsidy" policy, which offers financial assistance and professional training to support family caregivers, effectively addressing the aging population's challenges [47]. The challenges and obstacles in combining traditional filial piety culture with modern caregiving concepts mainly encompass conflicts in social cognition, caregivers' skepticism towards professional nursing care, the absence of trust between families and professional care institutions, the intensification of economic burdens, and uncertainties related to information access and service quality. These elements collectively form the primary barriers in the integration process of traditional culture and modern caregiving concepts [45]. Healthcare professionals should encourage family caregivers to care for the elderly with disabilities autonomously and spontaneously. At the national, community, and family levels, the culture of filial piety should be promoted so that every Chinese person identifies with the culture of filial piety, benefits from it, and further inherits the culture. It will increase caregivers' willingness to care, thereby reducing care risks.

Building and improving the respite care system to enhance support for caregivers in coping with care risks

The study found that 13 out of 22 caregivers reported heavy economic burdens and insufficient family and social support, similar to previous research [35]. Respite care, also known as temporary care, interim care, or provisional nursing, was a temporary care service designed to alleviate family caregivers' physical and mental stress [48]. Australia implemented an in-home care substitution service program [49]. Germany and Finland provided elderly individuals with social care insurance, offering them five weeks of home-based respite care and five days per month of institutional respite care, respectively [50]. Through respite services, these countries promoted aging in place, ensuring the sustainability of caregivers and the dedication of family caregivers. Sufficient funding sources were secured to maintain operations, ensuring the sustainable development of families with disabled elderly members and reducing the care burden on caregivers [50]. In China, the existing policies and regulations for elderly care services had primarily focused on supporting social elderly care and vigorously promoting social elderly care institutions, seemingly neglecting the needs and challenges of the vast population of elderly individuals who preferred to age at home, as well as the family caregivers who supported the home-based care system [51]. Additionally, respite care services in China were mainly being piloted in economically developed areas and were characterized by regional autonomy. In places such as the Northeast, Northwest, and Southwest, which were financially underdeveloped and faced significant elderly care challenges, respite care services were lacking [52]. Zhang Junxian [53] surveyed 111 family caregivers of disabled elderly individuals in Nanjing, China. The results revealed that 58.6% of the caregivers were unclear about the content of respite services, 71.2% were concerned about the quality of the services, 68.5% worried that the elderly would not adapt to them, and 59.5% were unaware of how to access respite services. Additionally, our country's implementation of respite care services faces other obstacles, including insufficient policy support, economic burden, social cognition, service quality, human resource availability, information asymmetry, cultural adaptability, and system construction [51]. These issues collectively constrain the popularization and quality improvement of respite care services, alleviating burdens on family caregivers and enhancing the quality of life for the elderly. The government should develop comprehensive policies that subsidize and support respite care, implement financial aid programs to alleviate economic burdens, conduct public education

campaigns to change societal perceptions, establish quality standards for services, train and recruit a professional caregiving workforce, create transparent and accessible information channels, adapt services to cultural contexts, and build a robust care system that promotes the widespread adoption and continuous improvement of respite care. These measures are essential to reducing the burden on family caregivers and enhancing their ability to perceive and manage care-related risks.

Strengths and limitations

This study employed qualitative methods to explore the characteristics and related factors of care risk perception among caregivers of homebound elderly individuals with disabilities to provide a reference for enhancing caregivers' ability to perceive care risks. However, this study had certain limitations. Firstly, this study was conducted solely in Zhengzhou City, Henan Province, China. However, there may be variations in socio-economic development, cultural backgrounds, eldercare policies, and measures across different regions. These differences can influence informal caregivers' caregiving methods and quality, affecting their ability to perceive care-related risks. Secondly, we only conducted one interview with each caregiver, thus limiting our depth of understanding of the subject. In future research, researchers should expand the sample size to analyze how regional economic levels, eldercare policies, and measures affect the perception of care risks by informal caregivers of elderly individuals. It will enhance the study's representativeness. Additionally, researchers should conduct multiple interviews with informal caregivers to understand the dynamic characteristics of their care risk perception. It will serve as a reference for developing intervention programs targeting the perception and coping strategies of care risks among these caregivers.

Implications for policy and practice

The results of this study revealed that informal caregivers for homebound elderly individuals with disabilities had a deficiency in perceiving care risks, which was impacted by a multitude of barriers. From a policy perspective, government departments should establish and refine the respite care system and implement financial assistance programs. From a clinical practice standpoint, healthcare professionals should strengthen communication with caregivers, provide timely and effective psychological support, and conduct training on care skills. This is aimed at enhancing the ability of informal caregivers for homebound elderly individuals with disabilities to perceive care risks, reduce care risks, and improve the quality of life for these elderly individuals.

Conclusion

The characteristics of risk perception among caregivers of homebound functionally dependent elderly individuals were influenced by factors such as past caregiving experiences, health literacy, and psychological status, resulting in significant individual differences. Moreover, most caregivers needed more risk perception capabilities and caregiving literacy, faced heavy caregiving burdens, and experienced inadequate family and social support. Future studies should consider caregivers and patients, prioritize relevant training to enhance caregivers' knowledge and skills, improve their perception of caregiving safety risks, establish and refine caregiver relief service systems, and alleviate caregiver burdens to enhance the caregiving experience.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12912-024-02211-5.

Supplementary Material 1

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Author contributions
Hq Z, Qh Z, and Lm L: Study design; Hq Z and Qh Z : data collection; Hq Z, Qh Z, Ty X and Xx W: data analysis; Lm L and Qf L: study supervision; Hq Z and Qh Z: manuscript writing; Xx W, Qh Z, Ty X, Ym Q, My ZS and Lm L: critical revisions for important intellectual content. All authors read and approved the final manuscript.

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Most data generated or analyzed during this study are included in this published article, and other data could be obtained from the corresponding author.

Data availability
Data is provided within the manuscript or supplementary information files.

Declarations

Ethics approval and consent to participate
The Zhengzhou University ethics committee in China approved all study procedures (approval number: ZZUIRB2021-78). This research has been performed in accordance with the Declaration of Helsinki, and all participants were aware of the study objectives and signed informed consent.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

Abbreviations
None.

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