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# The hidden costs of informal caregiving: a concept analysis

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## Abstract

**Background** “The hidden costs of informal caregiving” is an interdisciplinary concept. While caregivers make a significant contribution to the process of caregiving, they sacrifice their leisure time, and incur risks of dropping out of the job, impaired mental and physical health, and decreased well-being within the context of caregiving. Those invisible sacrifices are often overlooked and described as hidden costs of informal caregiving. However, the conceptualisation of hidden costs of informal caregiving has not yet been clarified and scientifically assessed. The research aimed to clarify the concept of hidden costs of informal caregiving and develop an operational definition.

**Methods** Walker and Avant’s concept analysis was conducted. Databases of CBM, CNKI, WanFang, VIP, PubMed, Embase, CINAHL, Web of Science, MEDLINE, Cochrane Library, Econlit, CINAHL and ProQuest were searched with the term “hidden costs of informal caregiving”. Information about the uses of the concept, defining attributes, model cases, antecedents, consequences and empirical referents of hidden costs of informal caregiving was extracted and synthesized.

**Results** A total of 25 articles were included. The six defining attributes of hidden costs of informal caregiving were identified as including “undertaken by informal caregivers”, “the time costs of caregiving”, “costs of career development” “physical well-being costs”, “mental well-being costs” and “social relationship costs”. Personal characteristics of the caregivers and care recipients, along with caregiving attributes, were among the antecedents. The consequences of hidden costs of informal caregiving resulted in negative influences which included poor quality of life, life-altering decisions, options for the type of care, some degree of economic hardship, decreased compliance with treatment plans and monetary value informal caregivers are willing to pay to be replaced.

**Conclusion** This concept analysis decisively illuminated the hitherto nebulous concept and expanded the contents of hidden costs of informal caregiving, which will foster a deeper appreciation of the invisible cost of caregivers. Moreover, it will provide a reference for the study of the hidden costs of informal caregiving in future, contribute to the development of assessment tools and theoretical models of hidden costs of informal caregiving, and create a basis for designing an evidence-based care program.

**Keywords** Hidden costs of informal caregiving, Concept analysis, Caregivers, Quality of life

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## Background

Caregivers play an important role in the process of patient care, which has been increasingly valued in the long-term care systems of countries worldwide [1]. They provided various care services such as assistance with activities of daily living, emotional support and disease management for those who have partially or completely lost the ability to take care of themselves due to acute or chronic illnesses [2–4]. From the perspective of the government, caregivers contribute to the reduction of global expenditures on elder care and alleviation of the pressure on global ageing [5]; however, inadequate support results in heavy hidden costs of informal caregiving for caregivers owing to their unpaid labour engaged in caregiving services [6]. The work of informal caregivers is very stressful and demanding. These caregivers might be vulnerable to depression, illness, physical exhaustion and mental fatigue. Their care work with the disabled also incurred additional care-related expenses, reduction of the individual's leisure time, caregiving-related work productivity loss [7], and impaired physical, emotional or social well-being [8–10].

“Hidden costs of informal caregiving” is an important concept for the management of impacts on informal elder care and quite a few academic researchers have devoted a lot of focus and endeavour to it. Nevertheless, there is little consensus on how to appropriately measure the

economic evaluations of informal care [11] and the “hidden costs of informal care” are still overlooked or underestimated by policymakers and researchers. In 1999, Fast et al. summarised all the costs of informal elder care, which attempted to focus the public view on the hidden costs of informal care [9]. Subsequently, the hidden costs involved were explored by researchers from different perspectives. For example, the hidden employment-related losses and the time value of unpaid labour caused by caregiving work were revealed from the viewpoint of labour supply [12, 13], and the damage to the overall health of caregivers was explored from the aspect of non-economic costs [6, 14–16]. In brief, the concept of hidden costs of informal caregiving hasn't reached a consensus and lacks systematic generalisation and clear elaboration of the concept.

Concepts often are discussed as key components of theory, and they occupy an important role in theory development [17, 18]. Concept analysis is a commonly used method for defining and exploring concepts [19]. Meanwhile, given the restricting definitions of hidden costs of informal caregiving, there will result in large measurement differences and difficulty in making comparisons, and it will inevitably limit the extent of costs reported [20], failing to recognize caregivers and their contributions, and contribute to caregivers' feelings of abandonment by society. Agreement on the meaning of “hidden costs of informal caregiving” is essential to recognize and optimally support the work of caregivers, and enhance the rigour of studies on hidden costs of informal caregiving.

Therefore, Walker and Avant's concept analysis was conducted to offer a deeper understanding of defining attributes, antecedent factors, consequences and measurement indicators of hidden costs of informal caregiving [21]. The aim was to provide a conceptual framework reference and establish a theoretical foundation for the quantification of hidden costs of informal caregiving.

## Methods

### Concept analysis methods

This concept analysis was conducted using the structured method of Walker and Avant's to conceptualise the hidden costs of informal caregiving and to classify its defining attributes, model cases, antecedents, consequences and defining empirical referents. The method involved eight steps, which provided a recognized methodological framework and a more objective approach to clarify the concept (Table 1) [22].

### Data sources

Owing to the hidden costs of informal caregiving belonging to the multidisciplinary area, so we chose databases that covered all subjects, which included CBM, CNKI,

**Table 1** Steps of Walker and Avant's concept analysis of hidden costs of informal caregiving

| Phases   | Specific Content   | Position     |
|--|--|--------------|
| 1. Select a concept  | Hidden costs of informal caregiving  | Introduction |
| 2. Determine the purposes of the analysis                                    | To clarify the concept of hidden costs of informal caregiving and develop an operational definition                              | Introduction |
| 3. Identify all uses of the concept  | Definitions and uses of hidden cost of care were scooped from various sources to reduce potential bias in understanding          | Methods      |
| 4. Determine the defining attributes   | Characteristics that were the most frequently associated with the concept of hidden costs of informal caregiving were identified | Results      |
| 5. Identify a model case   | Examples of hidden costs of informal caregiving that encompassed all the defining attributes                                     | Results      |
| 6. Identify borderline, -related, contrary, invented, and illegitimate cases | -  | Results      |
| 7. Identify antecedents and consequences                                     | Events that occurred before the occurrence of hidden care costs and the consequences of hidden care costs were identified        | Results      |
| 8. Define empirical referents  | Empirical measures of hidden costs of informal caregiving  | Results      |

WanFang, VIP, PubMed, Embase, Web of Science, MEDLINE, Cochrane Library and ProQuest. Besides, there would be common databases that were utilised within specific areas [23], such as Econlit in the Economic area and CINAHL in the nursing area. Articles published before July 31, 2024, were systematically searched for this analysis. The search strategies included MeSH terms and keywords (i.e., subject headings and/or free words) combined with the boolean logical operators such as “OR”, “AND”, etc. Full search strategies and search terms can be found in the supplemental material (Appendix 1 and Appendix 2).

Eligibility included articles that: (1) the subjects were informal caregivers who provide unpaid care; (2) research contents focused on the concept of hidden costs of informal caregiving and involved its defining attributes, antecedents, consequences, and measurements; (3) published from the time of database establishment until July 31, 2024; (4) research designs included mixed-methods, quantitative, qualitative or review. Articles were excluded if they: (1) were duplicate publications; (2) were unavailable to access the full text.

### Screening methods

Records were searched according to the search strategy and imported into the software EndNote 20 by removing duplicates, titles and abstracts of the articles were independently screened by two researchers (XS and YS) based on inclusion and exclusion criteria, finally full-text was reviewed to assess contextual information congruent with the concept and data on the definitions of hidden costs of informal caregiving and its attributes, antecedents, consequences and measurement methods were extracted from the included studies. Any uncertainty related to the paper selection was resolved through discussions between these two authors (XS and YS) and a third author (JJG) was consulted when consensus couldn't be reached.

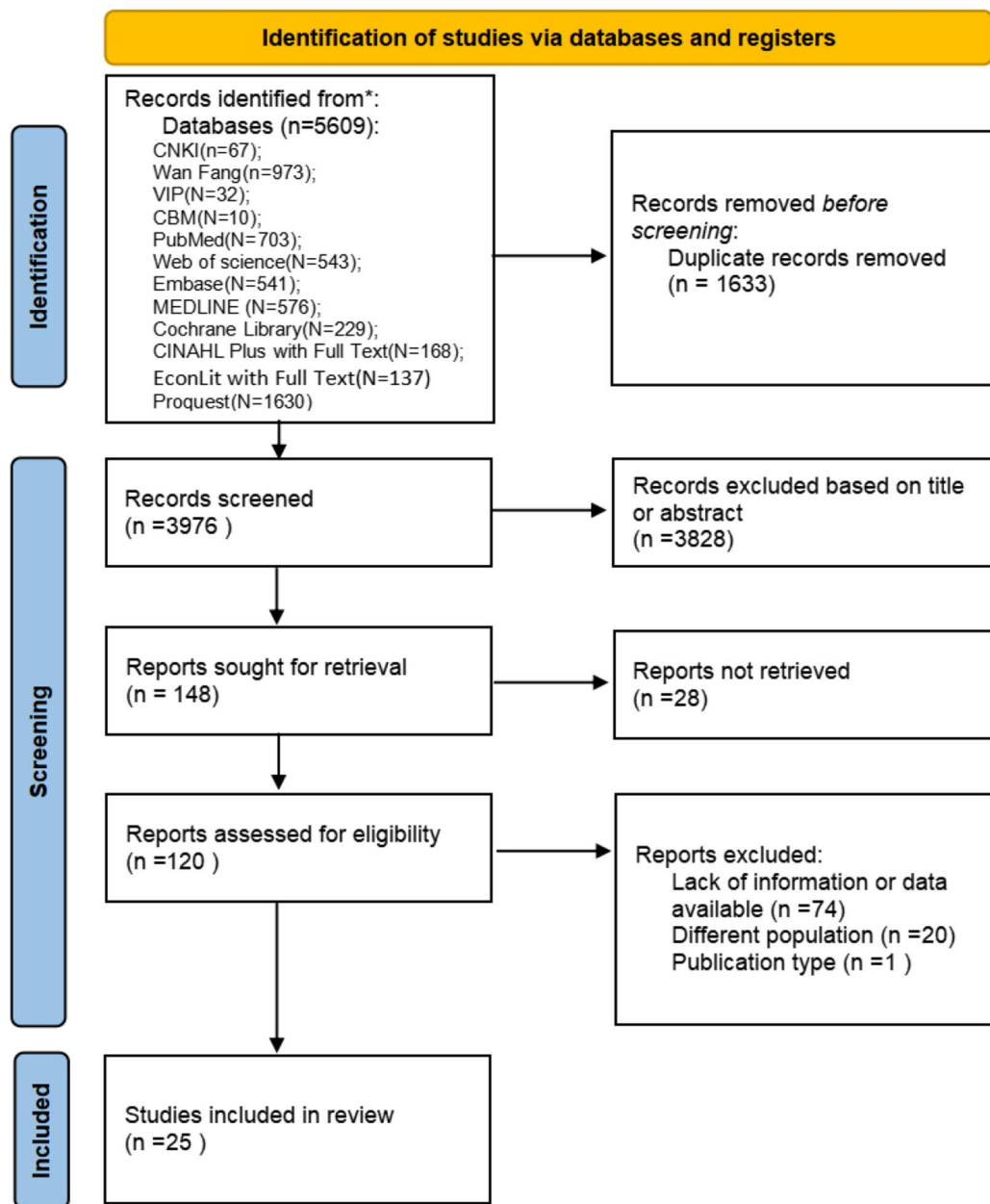
## Results

### Search results of included studies

A total of 5,609 records were retrieved from this database, with 3,976 articles remaining after 1,633 duplicates were removed by Endnote, and 148 articles were retained after initial screening of titles or abstracts ( $n=3828$ ); 95 records were excluded because they were inaccessible full-text ( $n=28$ ), did not correspond to the target population ( $n=20$ ), were published in the newspaper ( $n=1$ ) or did not include the concept of the hidden costs of informal caregiving ( $n=74$ ). 25 pieces of literature were finally selected, including 3 in Chinese and 22 in English (Fig. 1). Data on the definitions of hidden costs of informal caregiving and its attributes, antecedents, and consequences were extracted from the included papers (Table 2).

### Uses of the concept

So far, the specific concept of “hidden costs of informal caregiving” has not been commonly used or consistently described in the literature. Hidden costs were a concept opposed to explicit costs [10, 15]. In the area of economics, hidden costs always meant expenses that were not normally included in the purchase price for a piece of equipment or machine, e.g. maintenance, supplies, training, support and upgrades [8]. By contrast, it was all costs associated with either production or maintenance according to the dictionary of industrial terms [41]. The hidden costs were paid privately by individuals themselves rather than from the public purse [27]. Meanwhile, some investigators have invested efforts in the hidden costs in the sphere of caregiving. In an attempt to draw attention to the hidden costs of informal elder care, Fast et al. first categorised all costs in informal elder care as economic costs (employment-related costs, out-of-pocket expenses, and unpaid labour) and non-economic costs (mental well-being, physical well-being, and social well-being) [9]. However, it didn't clearly distinguish the hidden costs of informal caregiving separately and indicate the definition of the concept. Subsequently, the hidden costs of informal caregiving were classified by the researchers more concretely. Except for direct costs, the effects of physical, mental health and social well-being were described as “intangible costs” [36, 40], and the unpaid labour costs and employment-related losses of care were included in the indirect costs [13, 39]. The unpaid labour of care work was not paid, valued, or measured in economic terms, but it had significant impacts on the quality of life, opportunities, and choices of those who performed it and those who benefited from it. Therefore, unpaid labour could be seen as a form of hidden cost that was often overlooked or ignored in economic analysis and policy-making. Phipps and Burton described that the hidden costs were the “opportunity costs” of caregiving and included “giving up a paid job”, “working fewer hours”, and “not getting promoted” [28]. Opportunity costs of caregiving, lack of social relationships, and negative effects on caregiver's morale (i.e. grief, anxiety, pain and suffering) were also the aspects of hidden costs of informal caregiving [31]. Hidden costs of informal caregiving have entered the public view in recent years with the aggravation of population ageing in China. The hidden loss of caregivers' time, job opportunities and income levels, stress from caregiving, in physical and mental health and the potential social isolation caused by insufficient social participation were components of the hidden costs of informal caregiving [10]. Apart from these definitions, no further conceptual or operational understandings were identified.



**Fig. 1** Flow chart of the study selection process of concept analysis

### Defining attributes of hidden costs of informal caregiving

Defining attributes is important for concept analysis, which is a strategy that examines the features and meanings of a concept. A defining attribute is a characteristic or naming of the occurrence of a specific phenomenon that is essential for a concept to exist and distinguishes it from another similar or related one [22]. The defining attributes of hidden costs of informal caregiving were found by showing the characteristics that were the most frequently associated with the concept of hidden costs of informal caregiving. The results showed it had six

defining attributes, including “undertaken by informal caregivers”, “time costs on unpaid caregiving”, “career development costs”, “physical well-being costs”, “mental well-being costs”, and “social relationship costs” (Fig. 2).

### Undertaken by informal caregivers

The hidden costs of informal caregiving were not directly paid by the public sector or the formal health care system, but were often undertaken by caregivers [27, 37], who were from the care recipient’s social network (family members, friends, acquaintances or neighbours [30]. And

**Table 2** Data extraction of the concept of the hidden costs of informal caregiving

| Author, year  | Antecedents  | Defining attribute   | Consequences  |
|---|--|--|---|
| Varricchio, 1994 [24]   |  | 1) Loss of income;<br>2) Intangible human cost;  |   |
| Fast et al., 1999 [9]   |  | 1) Costs that seldom enter into discussions about health care and social policy;<br>2) Unpaid labour costs;<br>3) Non-economic costs:<br>such as physical, social, and emotional well-being; |   |
| Dewey et al., 2002 [25]                                       |  | 1) Time cost on informal care;<br>2) Work adjustments of paid workers: cessation of paid work; reduction of their work hours; available leave; rearrangements of their work schedules;       |   |
| Wagner and Lacey, 2004 [12]                                   |  | 1) Employment-related costs: lost wages, loss of opportunity for occupational promotions and advancement possibilities;<br>2) Unpaid labour of family caregivers;                            | 1) Compliance with a treatment plan: Patients' delayed diagnosis or accessible treatment;<br>2) Patient outcomes: inhibit the treatment regimen;<br>3) Family burden: the psychological toll of financial burden;<br>4) Employment: the inability to change jobs, losing insurance coverage or employment itself, or a hesitancy to pursue salary increases and promotions; |
| Chiò et al., 2006 [13]  | 1) Worsening of disability;  | 1) Cost of time on caregivers;   |   |
| Meyers & Durfee, 2006 [26]                                    |  | 1) The time devoted to unpaid caring work in the home;   |   |
| Ansello & Rosenthal, 2007 [27]                                |  | 1) The costs were paid privately rather than from the public purse;  |   |
| Phipps & Burton, 2009 [28]                                    | 1) Family structure;<br>2) Gender;<br>3) Characteristics of the care recipients: the severity of the condition, chronic condition, conditions with an early onset; | 1) Implicit costs in the form of foregone labour market opportunities;   |   |
| Sabes-Figuera et al., 2010 [29]                               |  | 1) The cost of time on unpaid care;  |   |
| Chatterjee, Riewpaiboon, Piyathakit, & Riewpaiboon, 2011 [30] |  | 1) Opportunity costs: foregone paid work, unpaid work and loss of leisure time;<br>2) Benefits that informal caregivers give up for informal care;<br>3) Time cost of unpaid caregiving;     |   |

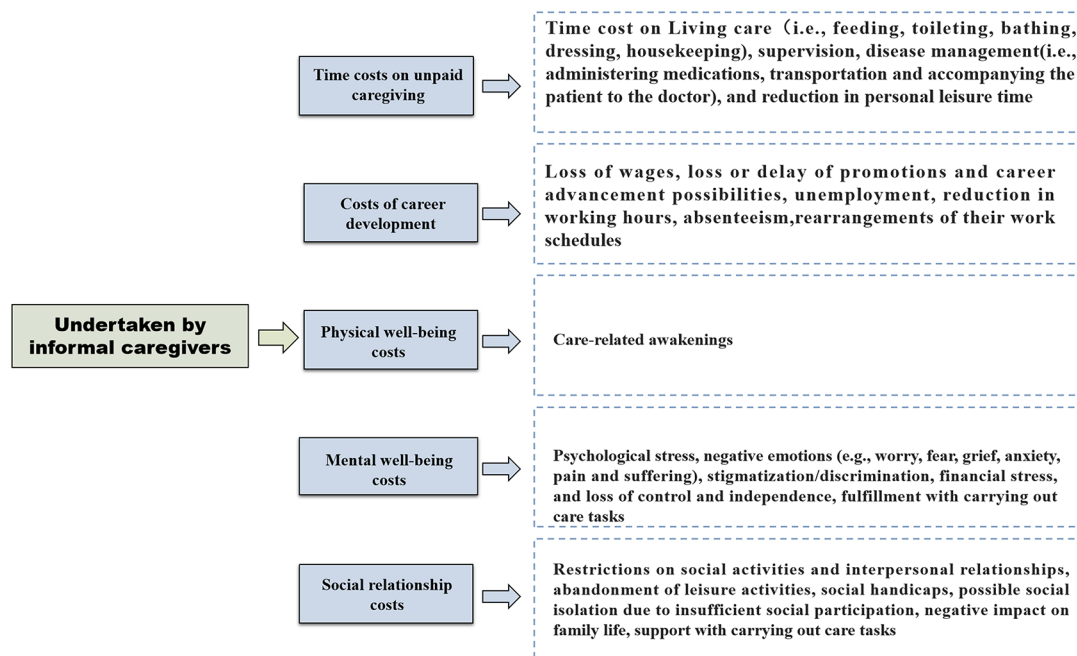
**Table 2** (continued)

| Author, year                           | Antecedents  | Defining attribute  | Consequences  |
|--|--|---|---|
| Gervès et al., 2013 [31]               |  | 1) Opportunity costs of the caring dimension;<br>2) Lack of social relationships: social handicap, fatigue, giving up leisure activities, and fewer social contacts;<br>3) Negative effects on caregiver's morale (such as grief, anxiety, pain and suffering); | 1) Negative influence of intangible impacts of caring on both informal caregivers' ability to estimate their WTP value and their willingness to pay (WTP) to be replaced; |
| Addo, Nonvi-gnon, & Aikins, 2013 [32]  |  | 1) Emotional suffering;<br>2) Leisure time;<br>3) Social relationship;<br>4) Fear;<br>5) Stigmatization/Discrimination;   |   |
| Silva et al., 2013 [16]                |  | 1) Feelings of anguish and concern;<br>2) Restrictions to the activities of daily life and leisure;<br>3) Thoughts of having lost the life they used to have;   |   |
| Colucci et al., 2014 [33]              |  | 1) Suffering, psychological stress, limitations to social relationships etc.  |   |
| Jowsey, Strazdins, & Yen, 2016 [34]    |  | 1) Worry;<br>2) Time cost on the caregiving activity;   |   |
| Opoku-Boateng et al., 2017 [35]        | 1) Gender<br>2) Educational degree   | 1) Indirect costs: productivity losses to caregivers;<br>2) Non-monetary costs such as stigma and pain;   |   |
| Stephen Tettey et al., 2017 [36]       | 1) Gender  | 1) Caregiving burden;<br>2) Financial stress;   |   |
| Chen et al., 2019 [6]                  |  | 1) Impacts on caregivers' employment decision-making, physical and mental health, and social capital accumulation;  | 1) Subjective well-being;   |
| Di, 2021 [15]                          | 1) Characteristics of the caregivers: working state, gender, marital status, age;<br>2) Caregiving attributes: intensity and duration of caregiving;   | 1) Impact of labour market: included impact on labour supply, caregivers' labour time and personal income;<br>2) The negative effects on caregivers' mental and physical health;  |   |
| Hongwei and Yanyu, 2021 [10]           | 1) Caregiving attributes: insufficient professionalism and lack of sufficient energy investment in caregiving;<br>2) Characteristics of the caregivers: non-working age, non-employed population (such as spouse); | 1) Cost of unpaid caregiving services;<br>2) Hidden loss to caregivers in terms of time, job opportunities and income levels;<br>3) Cost of health loss: such as psychological stress, physical and mental health stress, and potential social isolation;       | 1) Contribute to the strategic choices in home (community) care or institutional care;  |
| Bradley, Schlick, & Yabroff, 2022 [37] | 1) Time of caregiving;<br>2) Characteristics of the caregivers: such as employment or not, age, gender, lack of paid annual leave, inadequate preparation for carer roles;   | 1) The time cost of unpaid care;<br>2) Employment-related costs: including non-employment, reduced wages and earnings, missed workdays, and/or changes to lower paying jobs;<br>3) A decline in physical and mental health;                                     | 1) Poor quality of life;<br>2) Other life-altering decisions;<br>3) Financial impact hardship including increased debt and withdrawals from savings;                      |



**Table 2** (continued)

| Author, year                      | Antecedents                               | Defining attribute  | Consequences                                   |
|-----------------------------------|---|---|--|
| Robbins et al., 2022 [14]         |   | 1) Caregiving-related awakenings;   |  |
| Kotzeva et al., 2023 [38]         |   | 2) Caregiving-related work productivity impairment;   |  |
|                                   |   | 1) Intangible costs: including the pain, suffering, stress, and anxiety;  |  |
|                                   |   | 2) Caregiver cost: loss of productivity (presenteeism, absenteeism, permanent disability, unemployment, early retirement) and forgone leisure time;       |  |
|                                   |   | 3) Constraints on social activities;  |  |
|                                   |   | 4) Negative effects on family life;   |  |
|                                   |   | 5) Feelings of loss;  |  |
| Xiaoxiao, 2023 [39]               |   | 1) Opportunity costs of care: reduction in working hours and leisure time, relinquishing or delaying career promotion, withdrawal from the labour market; | 1) Weaken family function in economic support; |
|                                   |   | 2) Social isolation;  |  |
|                                   |   | 3) Social exclusion;  |  |
| Tahami Monfared et al., 2024 [40] | 1) Higher education;                      | 1) Fulfillment with carrying out care tasks;  |  |
|                                   | 2) Age;                                   | 2) Support with carrying out care tasks;  |  |
|                                   | 3) Advanced disease severity of patients; | 3) Relational problems with care recipient;   |  |
|                                   | 4) Type of disease of care recipients;    | 4) Problems with own mental health;   |  |
|                                   |   | 5) Problems combining care tasks with daily activities;   |  |
|                                   |   | 6) Financial problems because of caring tasks;  |  |
|                                   |   | 7) Problems with own physical health;   |  |



**Fig. 2** Defining attributes of hidden costs of informal caregiving

these groups provided unpaid care to older adults, disabled, or chronically ill relatives or friends. Informal care carried a number of hidden costs that were seldom discussed in health and social policy [6].

**Time costs of unpaid caregiving**

Even though the care services were commonly unpaid labour, their economic value cannot be ignored. Evidence showed that the cost of the time spent by caregivers on caregiving activities accounts for a significant proportion of the cost of care [25, 29, 34]. Indirect cost (cost of time spent on caregiving) constituted about 34% of average

and total costs [36]. The caregivers spent the majority of their time on feeding, toileting, bathing, dressing, administering medications, supervision, housekeeping, and transportation, including accompanying the patient to the doctor, providing family help and other tasks in the process of care [13]. They also had a reduction in personal leisure time [40].

**Costs of career development**

Employed caregivers might lose wages, be unemployed and absent from work, have the inability to leave a position for fear of losing insurance coverage, and lose

promotions and career advancement possibilities owing to the care service [12, 24, 25]. The provision of home care had an impact on the labour supply in the labour market, rearrangements of their work schedules, labour time and income of caregivers [15, 24, 28].

#### **Physical well-being costs**

In the records of hidden costs of informal caregiving, the impact on the physical health of caregivers was rarely mentioned. Only one reported that caregiving-related awakenings were a common problem among caregivers [14]. Fatigue also be considered into hidden costs [31].

#### **Mental well-being costs**

The effects of caregiving focused on the negative effects on caregivers' mental health in the early stage of care service [15, 37]. They faced psychological stress [33], poorer morale (i.e., worry, fear, grief, anxiety, pain and suffering) [16, 31, 33, 34], loss of control and independence [9], and stigmatization/discrimination [32]. It was demonstrated about 87% reported a high level of financial stress as a result of caregiving [36]. Research demonstrated that the mean score of emotional suffering for their family members was the highest [32]. Fulfillment with carrying out care tasks was a positive indicator of hidden costs of informal care [40].

#### **Social relationship costs**

Social well-being is a multi-factorial construct that includes different components of the social environment and could result in an overall positive assessment of one's social life [32, 42]. Due to the demands and responsibilities of caregiving, the caregivers had limitations in interpersonal relationships and social activities [9, 16, 37], and they were exposed to risky circumstances of social handicaps, fewer social contacts and potential social isolation caused by insufficient social participation [15, 31]. It also had a negative impact on family life [38]. By contrast, others can be supported in carrying out their caring tasks, which has positive implications for reducing the hidden costs of care [40].

### **Cases of hidden costs of informal caregiving**

#### **Model cases**

Yang Li, a 45-year-old public school teacher, lives in a village and earns a modest income. She is also the primary caregiver for her 75-year-old mother, who suffers from Alzheimer's disease. She devotes about four hours a day to taking care of her mother with daily activities such as bathing, dressing, feeding, and taking medications. She also accompanies her mother to the doctor's appointments, which are often far from her home and require public transportation. The caregiving responsibilities have affected her work and career prospects.

She frequently arrives late or early departure for the care work. Some opportunities for professional development or training are declined because of her limited energy and time. And she feels exhausted, stressed, and depressed most of the time. She has no time or energy for herself. She feels isolated and lonely, as she has no friends or relatives who can help or support her. She feels trapped and hopeless, as she sees no way out of her situation. Having to keep a constant eye on her mother's movements during the night, she is often unable to sleep and is at risk of frequent night wakings. At the same time, her back is damaged due to prolonged labour such as turning her mother.

#### **Borderline case**

A borderline case has some but not all the concept attributes [43]. Ming Wang is 63 years old and spends almost the entire day caring for his wife with a disability. He doesn't usually have much social interaction, only occasional telephone contact with former colleagues, and usually wakes up often during the night and doesn't get enough sleep. This case lacks important attributes of the hidden costs of informal caregiving, including employment-related costs. What Ming Li also lacks are costs physical well-being costs and mental well-being.

### **Identification of antecedents and consequences**

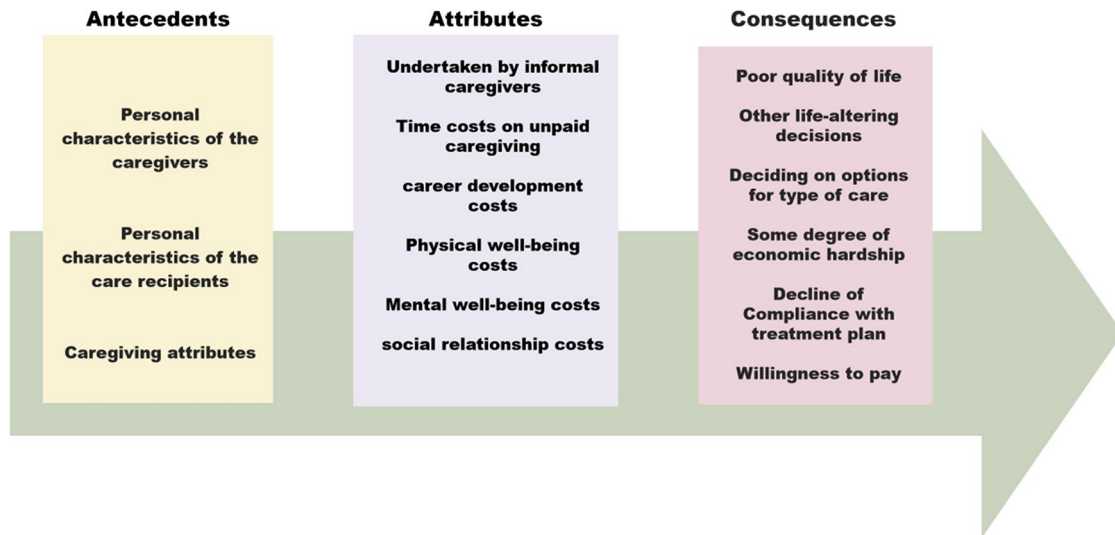
#### **Antecedents of hidden costs of informal caregiving**

Antecedents are those events or incidents that must occur or be in place prior to the occurrence of the concept [22]. Through a comprehensive literature review, personal characteristics of care recipients and providers and caregiving attributes were the antecedents of the hidden costs of informal caregiving (Fig. 3).

#### **Personal characteristics of the caregivers**

The differences in the personal characteristics of caregivers led to different levels of adaptability and resilience of the care competence, thus resulting in different degrees of hidden costs of informal caregiving. Studies showed that age, gender, educational degree, employment status, family structure and marital status were all antecedents of hidden costs of informal caregiving [15, 35–37, 40]. Intangible costs increased with age of caregivers [40]. Women bear a heavier burden of the hidden costs of informal caregiving [36, 37]. The analysis revealed that the burden in caregiving was significantly higher for women (61%) than for men (39%) [35]. Better-educated caregivers reported lower indirect costs (i.e. productivity losses) [35] and intangible costs [40]. Employed caregivers had higher levels of financial and emotional distress [37]. People of non-working age and not in employment (e.g. spouses) had hidden costs when they provided care services for the disabled that were not





**Fig. 3** The antecedents, attributes and consequences of hidden costs of informal caregiving

turned into actual financial expenses for the household [10]. Lone parents are 5.5 percent more likely than married parents to have quit working and 8.6 percent more likely to have been unable to take a job [28].

#### ***The personal characteristics of the care recipients***

Results reflected that only one characteristic of care recipients influenced the hidden costs of informal caregiving. The worsening of disability was an antecedent to the hidden costs of informal caregiving [13, 28, 40].

#### ***Caregiving attributes***

Caregiving attributes involve type, time, intensity, and duration of caregiving, as well as nonprofessional care skills, insufficient energy investment, and inadequate preparation for the carer roles of the caregivers [10, 15, 37].

#### ***Consequences of hidden costs of informal caregiving***

Consequences refer to those events or incidents that occur because of the occurrence of the concept [22]. The consequences of hidden costs of informal caregiving included resulting in poor quality of life, other life-altering decisions, deciding on options for the type of care, some degree of economic hardship and decline of compliance with a treatment plan, and willingness to pay.

#### ***Poor quality of life***

The hidden costs of informal caregiving had a great impact on the quality of lives of the caregivers and their families because financial concerns could be a source of great worry and stress for patients and could produce long-term effects [12, 37].

#### ***Other life-altering decisions***

The hidden costs of informal caregiving might influence the caregiver's other life-altering decisions, such as savings or retirement account withdrawals and home sale or refinancing the consequences of which remained long after the patient was deceased [37].

#### ***Deciding on options for the type of care***

The hidden costs of informal caregiving could influence the strategy choice for home (community) care or institutional care of the patients. Home care (community) care is not cheap, hidden costs of informal caregiving undertaken by individuals and families should be accounted for when the governments develop public policies [10].

#### ***Some degree of economic hardship***

The hidden costs of informal caregiving would produce a long-term financial impact and result in some degree of economic hardship [39]. Productivity loss issues in the workplace for caregivers resulting from caregiving activities also might contribute to the decline in wages [14].

#### ***Decline of compliance with a treatment plan***

Patients might delay the care recipient's diagnosis or accessible treatment, or change the treatment regimen because of the huge hidden costs of informal caregiving [12].

#### ***Unwillingness to pay***

"Unwillingness to pay" referred to the unwillingness of informal caregivers to pay a certain amount of money in exchange for someone else providing care in their place [31]. Evidence showed that caregivers' willingness to pay (WTP) value is negatively associated with positive intangible impacts of informal care [31].

### Empirical referents

Empirical referents were classes or categories of actual phenomena that, by their existence or presence demonstrate the occurrence of the concept itself [22]. They are how you can recognize or measure the defining characteristics or attributes. In many cases, the defining attributes and the empirical referents would be identical. A validated tool to identify the hidden costs of informal caregiving remained undeveloped. Yet, to measure the hidden costs of informal caregiving, the time cost of caregiving, employment-related costs and the cost of quality of life (physical well-being, emotional well-being and social well-being) dimensions that involved interrelated problems needed to be taken into consideration. Currently, existing literature suggests that instruments for measuring hidden costs of informal caregiving do not yet cover all types of hidden costs. Currently, the measurement of the cost of care time is a major way, and there were also measurements involving individual dimensions such as quality of life, such as self-administered questionnaires to measure the amount of time caregivers spent on various caregiving activities within a typical week [29], subjective well-being scale [6], two sleep-related variables [14], the work and productivity and activity impairment (WPAI) questionnaire [14], the Caregiver Activity Time Survey (CATS) [13], CarerQoL-7D [40], the Client Service Receipt Inventory [29], and 12-item Zarit burden interview (ZBI) tool [36]. Existing research tools did not entirely reflect the classical characteristics of hidden costs of informal caregiving, which masked the holistic presentation of hidden costs of informal caregiving.

### Discussion

Generally, the hidden costs of informal caregiving have gradually attracted the attention of scholars worldwide, but there were still some challenges. All the concepts related to hidden costs of informal caregiving existing in the literature were reviewed and explained. Defining attributes, antecedents, consequences, and empirical references of the hidden costs of informal caregiving have been identified to present the progress of current research on the concept of hidden care costs.

Six defining attributes of hidden costs of informal caregiving align with what the caregivers experienced, and hidden costs of informal caregiving wouldn't exist without them. Meanwhile, there were no measurement tools for the hidden costs of informal caregiving, the existing measurement couldn't cover all the attributes of the hidden costs of informal caregiving, but only reflected a single dimension, such as the costs of time in the process of caregiving and other scales related the physical, emotional or social well-being [6, 14, 29, 35, 36, 44]. The development of the hidden costs of informal caregiving scale can help to address the shortcomings of existing

assessment tools and provide a more comprehensive assessment of the costs of care. Hidden costs of informal caregiving are often overlooked or underestimated due to their hidden nature and difficulty in quantifying. In future research, a scale for the hidden costs of informal caregiving could be developed based on these six conceptual attributes to quantify the hidden costs of informal caregiving, which are often not easily observed or measured directly but have a substantial impact on caregivers and their families. These can provide a more comprehensive assessment of care costs and promote society's awareness of hidden care costs. In subsequent studies, the specific dimensions of the scale can be identified after qualitative interviews with a specific group of caregivers. The scale is initially set as a self-assessment scale and will be used by community workers or social organisations to prioritise the allocation of resources to ensure that carers most in need of help are supported. Its exact ways of work can be explored and determined in further qualitative research.

The results of the literature review showed that the antecedents of the hidden costs of informal caregiving included personal characteristics of care recipients and providers, as well as caregiving attributes. However, there might be more factors undiscovered, which could also affect the hidden costs of informal caregiving, such as factors of interpersonal level or community level [45]. Therefore, further research needs to explore these potential factors and their relationships with the hidden costs of informal caregiving. This is important for understanding and evaluating the actual extent of the hidden costs of informal caregiving, as well as developing effective policies and interventions to reduce the hidden care cost of informal caregivers based on the defining factors. Although some countries have implemented interventions for caregivers, it is still necessary to explore the effectiveness of the control of hidden costs of informal caregiving. Improving access to optimal care or interventions (such as early interventions for people with arthritis or back pain, managing chronic pain earlier, could mitigate the need for a carer) and improved respite options are effective strategies to solve these problems in Australia [46]. Caregiver support services in Singapore can enhance the well-being of caregivers supporting people with intellectual disabilities across the lifespan [47]. Meanwhile, experiences from Sweden, Ireland, and the United States give the reference for the support of informal caregivers, such as national strategies or rights of caregivers, support for working caregivers (i.e., financial support, flexible work hours, paid leave), financial support for non-working caregivers, home care services for care-recipient and caregiver or legislation entitling caregivers and so on [47, 48]. It can be seen that these are all policy-based controls on the hidden costs of informal caregiving, and the identification of the influencing

factors of hidden costs of informal caregiving allows for more detailed intervention strategies to be implemented for caregivers, thus accurately regulating the hidden costs of informal caregiving.

There are some key recommendations for applying the concept of hidden costs of informal caregiving in future research and clinical practice. Further qualitative research is required to fully understand and define hidden costs of informal caregiving. The personality of care recipients and providers, and caregiving attributes are the proven factors that influence the hidden costs of informal caregiving. Thus, it should be considered in the conceptual examination. It is essential to understand why some individuals have low hidden costs of informal caregiving while others succumb to challenges of high hidden costs and to discover underlying factors that either strengthen or weaken the hidden costs of informal caregiving. Moreover, the concept analysis showed that the economic impact of caring activities on informal caregivers has been included to measure intangible costs [36, 40], and there is no clear explanation as to whether this portion of the economic impact is directly calculable as a result of paying for care spending, or indirectly generates an economic loss that cannot be measured, so qualitative studies are necessary to further finalize the preliminary conceptual model of hidden costs of informal caregiving, which can guide the exploration of the measurement tool and cost-based interventions for caregivers.

There are some limitations in the methodological part of the concept analysis. Owing to the limitations of the Walker and Avant's concept analysis, no specific criteria for evaluating the quality of literature was used in concept analysis, which may affect the reliability and validity of the findings. Therefore, details of methods were shown in the research to ensure the reliability of results as far as possible. Besides, literature involving informal caregivers was included in the study, but the concrete characteristics of the care recipients are not restricted, this means that the findings may not adequately reflect the hidden costs of caregivers of specific groups (e.g. the children, older adults, patients with specific illnesses). So qualitative study can be carried out further to add more details of the hidden costs. Moreover, the authors acknowledge that additional materials possessing relevance for this analysis may have arisen after the initial literature review, and may have been excluded from this concept analysis.

## Conclusions

The hidden costs of informal caregiving are not directly paid by the public sector or the formal healthcare system, and there was little consensus in the literature on the meaning of the terms. The concept analysis verified that these costs include “undertaken by informal caregivers”, “the time cost of caregiving”, “costs on career

development” “physical well-being costs”, “mental well-being costs” and “social relationship costs”. The definition and the proposed empirical referents of all attributes identified can be used to measure the hidden costs of informal caregiving and develop theory-driven interventions. Further research on hidden costs of informal caregiving should develop a measurement tool and interventions in specific populations.

## Abbreviations

|                    |   |
|--------------------|---|
| WPAI questionnaire | The Work and Productivity and Activity Impairment |
| CATS               | The Caregiver Activity Time Survey                |
| ZBI                | Zarit Burden Interview                            |

## Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12912-024-02293-1>.

Supplementary Material 1  
Supplementary Material 2  
Supplementary Material 3  
Supplementary Material 4

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## Author contributions

JJG: Research design; Methodology-Data retrieval, screening and extraction; Writing-original draft; Writing - review&editing. XS and YS: Methodology-Data retrieval, screening and extraction; SSW, PPW and LML: Involved in specifically critical review, commentary and revision; YHL: Participated in language editing and polishing. PW: Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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## Data availability

The datasets used and/or analysed during the current study are available from the corresponding author upon reasonable request.

## Declarations

### Ethics approval and consent to participate

Not applicable.

### Consent for publication

Not applicable.

### Competing interests

The authors declare no competing interests.

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