

# “Informal Caregiver” in Nursing An Evolutionary Concept Analysis

**Aimee R. Castro, MSc(A), RN; Antonia Arnaert, PhD, RN;  
Karyn Moffatt, PhD; John Kildea, PhD; Vasiliki Bitzas, PhD, RN;  
Argerie Tsimicalis, PhD, RN**

The informal caregiver experience has surged as a research topic in health care, including in nursing. However, the “informal” language is controversial, lacking conceptual clarity. Without a common understanding of who an “informal caregiver” may be, nurses may fail to consistently identify informal caregivers requiring support. Therefore, a concept analysis of “informal caregiver” was conducted on the basis of a sample of 20% of relevant nursing literature. The analysis of the attributes, antecedents, consequences, and contexts associated with “informal caregiver” offers a foundational guide for the ongoing development of nurses’ understanding of the informal caregiver role. **Key words:** *caregivers, concept analysis, definition, informal caregivers, nursing*

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**Author Affiliations:** *Ingram School of Nursing, McGill University, Montreal, Québec, Canada (Ms Castro and Drs Arnaert, Bitzas, and Tsimicalis); Integrated Health and Social Services Centre de l’Outaouais (CISSS), Gatineau, Québec, Canada (Dr Arnaert); School of Information Studies, McGill University, Montreal, Québec, Canada (Dr Moffatt); Gerald Bronfman Department of Oncology, McGill University, Montreal, Québec, Canada (Dr Kildea); Geriatrics and Palliative Care, Jewish General Hospital, Montreal, Québec, Canada (Dr Bitzas); and Shriners Hospitals for Children-Canada, Montreal, Québec, Canada (Dr Tsimicalis).*

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**F**AMILY-CENTERED care, including care of patients’ informal caregivers, is part of the nursing role.<sup>1</sup> Furthermore, nurses are expected to ensure that patients receive continuity of care even after discharge, which in many instances depends on the abilities of patients’ informal caregivers.<sup>2</sup> Over the past few decades, there has been a surge in research to better understand the needs and experiences of informal caregivers so that nurses and other clinicians can better support them.<sup>2,3</sup> Yet, issues in communication between families and health care workers may arise with the use of the concept of “informal caregiver.”

Currently, there is debate in health care circles regarding the meaning of this concept and the appropriateness of using “informal” for describing patients’ caregivers.<sup>4,5</sup> When a discipline does not share a deep understanding of a concept, the concept may be

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*sions of this article on the journal’s Web site ([www.advancesinnursingscience.com](http://www.advancesinnursingscience.com)).*

**Correspondence:** *Aimee R. Castro, MSc(A), RN, Ingram School of Nursing, McGill University, 680 Sherbrooke West, Ste 1800, Montreal, QC H3A 2M7, Canada ([aimee.castro2@mail.mcgill.ca](mailto:aimee.castro2@mail.mcgill.ca)).*

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### **Statements of Significance**

#### **What is known or assumed to be true about this topic?**

In recent decades, health care and nursing scholars have been studying the needs and experiences of supposed informal caregivers with mounting interest. Such research is of particular salience to nurses, as nurses spend significant time with families, partnering and caring for individual patients as well as their entire families. Despite the common use of the term “informal caregiver,” the “informal” language is controversial, and the concept is loosely defined. Without a consistent understanding of who informal caregivers may be, nurses may fail to recognize informal caregivers who need support in their caregiving roles. This inadequate recognition may contribute to the invisibility of informal caregiving work and feelings of abandonment and distress experienced by many informal caregivers.

#### **What this article adds:**

We conducted a concept analysis of the term “informal caregiver” to provide a more nuanced understanding of the concept. A sample of 20% of literature from 1986 to 2021 offered a starting point for a shared foundational understanding of “informal caregiver” in nursing. In these publications, we identified “role” as the main attribute of “informal caregiver,” which was informal and dyadic. The concept antecedents consisted of a pre-existing relationship with a person requiring care for a functional dependency due to a health- or aging-related condition. Role consequences resulted in numerous responsibilities with health and social implications for the informal caregiver/care receiver dyad. These consequences were often experienced negatively when dyads did not have access to adequate community health and social supports. The findings

direct nurses’ attention toward critically analyzing their use of this concept. This analysis can help identify the current limits of the concept and reveal unintentional omissions in its usage, enabling nurses to better identify and support informal caregivers and care receivers. To our knowledge, no other concept analysis of “informal caregiver” has been conducted, either in nursing or in allied health literature. With a common understanding of how the concept is currently used and of how it might evolve, nurses may be better equipped to recognize and support informal caregivers in practice and research.

inconsistently applied by practitioners of the discipline, such as by different practitioners of nursing. Hence, the support needs of informal caregivers may be overlooked or inconsistently addressed if their roles do not match with the assumptions of nurses.<sup>6</sup> For instance, given the gendered nature of caregiving and aging populations, nurses may assume that all informal caregivers are older adult women, ignoring those who may be male, younger, or unrelated to the patient.<sup>7,8</sup> The informal nature of the role could also lead nurses to assume that informal caregivers are simply family or friends visiting with patients, leading nurses to overlook informal caregivers’ knowledge and contributions to patient care.<sup>6,9</sup> Failure to recognize informal caregivers and their contributions renders their work invisible and unsupported, contributing to caregiver feelings of abandonment by nurses and society.<sup>6,9-11</sup> Furthermore, in intervention research for informal caregivers, the concept is inconsistently defined and measured, limiting the external validity of the study conclusions.<sup>2</sup>

Agreement on the meaning of “informal caregiver” is essential to recognize and optimally support the work of informal caregivers, enhance rigor of informal caregiving studies, and advance empirical efforts to improve nursing-led assessments and

interventions benefiting patients and their informal caregivers.<sup>2</sup> Therefore, a concept analysis of “informal caregiver” was conducted to offer a deeper understanding of (1) how nursing has been using this concept, that is, what was “the common manner of employing the concept”<sup>12(p82)</sup> in the sampled nursing literature; and (2) how the concept may evolve in the future, generating implications for future applications of the concept in practice and research.

**METHODS**

**Design**

This study was conducted using Rodgers’<sup>12</sup> evolutionary view of concept analyses. Concept analyses are used to learn the essence of a concept, providing a more nuanced and well-defined understanding of what the concept means.<sup>12</sup> According to Rodgers, clusters of attributes, antecedents, consequences, and contextual factors give meaning to evolving concepts across time periods, professional disciplines, and social contexts.<sup>12</sup> As the informal caregiver concept has been increasingly used and studied over recent decades in the discipline of nursing,<sup>2,3,13</sup> this design was appropriate.

**Search strategy and selection criteria**

The detailed search strategy and the inclusion and exclusion criteria used in this

concept analysis are displayed in Tables 1 and 2. To ensure that the data-sampling population was highly specific to the nursing discipline, the search was restricted to CINAHL, the predominant nursing and allied health academic database. Search terms relating to “informal,” “caregiving,” and “definitions” or “reviews” in titles, abstracts, and subject headings were used to search the CINAHL database for relevant literature. Moreover, references were excluded from the returned literature if they did not have Nurs\* in the journal title. No search restrictions were placed for language, publication date, or peer review. All references deemed eligible for inclusion were sorted by year. These references were subsequently selected to ensure that 20% of the retrieved nursing literature was included over time by selecting every fifth record, as per Rodgers’ methodology.<sup>12</sup>

**Data extraction and analysis**

Rodgers recommends that thematic analysis be delayed until the main data sources are collected to avoid premature commitment to an analytical structure.<sup>12</sup> Therefore, all included manuscripts were first retrieved and read in their entirety for preliminary data immersion.<sup>12</sup> The texts were then analyzed for any usage of the concept by any nurses featured in the literature: that is, how

**Table 1.** CINAHL Search Strategy Used to Identify Literature Sampling Population<sup>a</sup>

Subsearch Numbers	Search Strategy
S1	(MH “Caregivers”) AND [(MH “Scoping Review”) OR (MH “Concept Analysis”)]
S2	(TI “Informal”) AND (MH “Caregivers”)
S3	TI (“Informal” or “Lay” or “Volunteer”) N4 care* N4 (Concept* or Defin* or “Terminology” or “Analysis”)
S4	AB (“Informal” or “Lay” or “Volunteer”) N4 care* N4 (Concept* or Defin* or “Terminology” or “Analysis”)
Final search	S1 OR S2 OR S3 OR S4

<sup>a</sup>In CINAHL, “MH” means that both major and minor CINAHL subject headings were searched. “TI” refers to a search for terms found in the reference “Title.” “AB” refers to a search for terms found in the “Abstract.” “Nx” is a proximity searching operator, with × representing the number of words allowed nearby. For instance, “N4” indicates that the terms being searched will be within 4 words of each other. “S” refers to “the subsearches,” which were combined using the “OR” operator, generating the final search.

**Table 2.** Inclusion and Exclusion Criteria

	<b>Inclusion Criteria</b>	<b>Exclusion Criteria</b>
Article focus	The needs or experiences of informal caregivers were a focus of the publication, as indicated in the title or abstract.	The needs or experiences of informal caregivers were only peripherally related to, or not relevant at all to, the purpose of the publication.
Publication type	Literature reviews, theoretical papers, empirical studies, and commentaries longer than 1 page or more.	Abstracts and commentaries less than 1 page, as we deemed these texts to be too short to offer a deep understanding of the use of the “informal caregiver” concept.
Title	Published in an explicitly stated nursing discipline journal, with “Nurs*” in the journal title, where * represents variations on “Nurse” (eg, nurse, nurses, nursing).	Published in a journal without “Nurs*” in the title.
Percentage of the literature	20	80
Chronological selection	Every fifth reference from the 236 references listed in chronological order.	Removed every first, second, third, and fourth reference from the references listed in chronological order.

nurse participants used the concept in study results; or how authors of these nursing manuscripts used the concept when discussing their results or related nursing and caregiving literature.

The full-text data from each manuscript pdf file (ie, manuscript introductions, methods, results, conclusions, discussions, and any commentary data) were copied into Microsoft Excel. Each paragraph was pasted into its own cell, although paragraphs were sometimes split or duplicated if the text was relevant to multiple category labels. Each row of data was deductively coded if the data could fit under any of the data analysis categories suggested by Rodgers: attributes, antecedents, consequences, any other contextual factors, surrogate terms, and related concepts.<sup>12</sup> Data were categorized as “attributes” if the data discussed core-defining features of the concept that occurred repeatedly.<sup>12</sup> “Antecedents” was used to categorize data discussing features or events that had to be present prior to the oc-

currence of the concept.<sup>12</sup> “Consequences” was used to label data describing incidents or events that happened after or due to the presence of the concept.<sup>12</sup> “Contextual factors” was used to label other recurring themes surrounding the use of the concept, such as temporal patterns, social contexts, and linguistic nuances.<sup>12</sup> “Surrogate terms” referred to words or phrases that were synonyms of the concept.<sup>12</sup> “Related terms” was used to categorize any words or phrases that were similar to the concept under study but which differed by one of the attributes or defining features.<sup>12</sup> The category of “Other” was sometimes used as a placeholder for data that seemed relevant to defining the concept but required further reflection as to which Rodgersian category the data fit into best.

These categories of data were then clustered in Excel to identify labels for any sub-themes describing each main category. Next to each category, a few additional potential descriptors or details of the category were added that were referenced in the text data

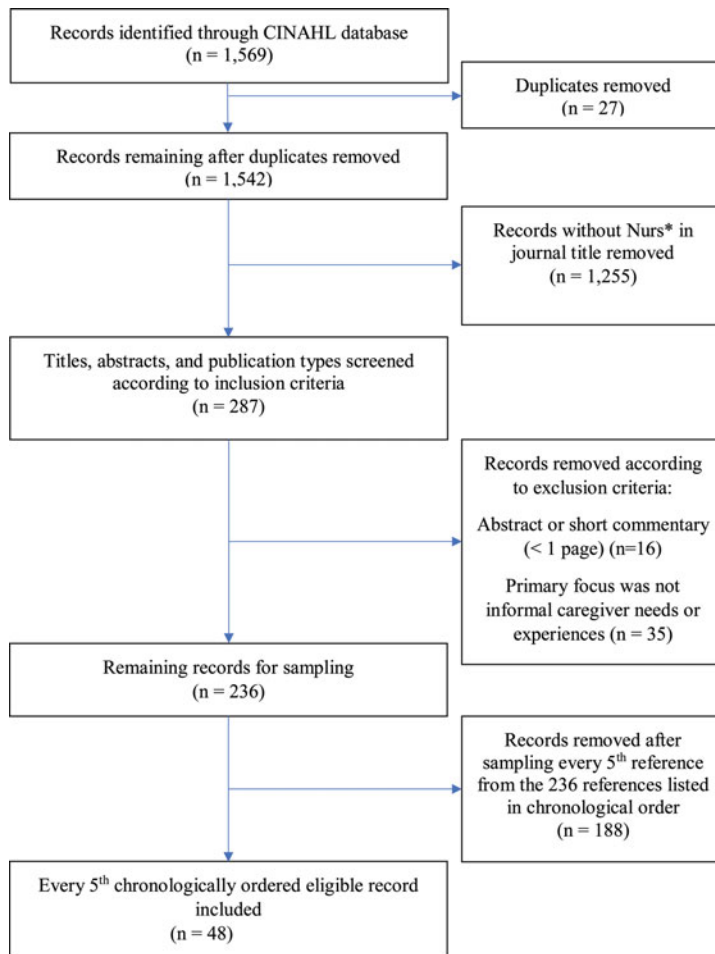
(eg, "consequences—effects on caregiver—physical"). Similar ideas in the literature were grouped, reorganized, and relabeled by row, until we had generated cohesive descriptors for each category.<sup>12</sup> Supplemental Digital Content 1, available at: <http://links.lww.com/ANS/A46>, provides examples of the data analysis process, illustrating how data were reorganized to generate the final labels of the subthemes.

**RESULTS**

**Search results**

The CINAHL search was conducted in July 2021 (Figure). A total of 1569 references

were screened. After excluding 27 duplicates and 1255 records published in journals that did not have "Nurs\*" in the title, 287 titles and abstracts were screened. Abstracts and commentaries less than 1 page were excluded because these designs were deemed too short to explore nurses' use of the concept. Furthermore, 35 manuscripts were excluded when the abstract indicated that informal caregiver needs or experiences were not the primary focus of the publication. Of 236 eligible publications, every fifth record was included resulting in 48 publications. This sample size surpasses the suggested minimum of 30 references for a Rodgerian concept analysis.<sup>12</sup> The earliest eligible



**Figure.** Search results.

manuscript was published in 1986. These manuscripts were written in 18 countries. The study designs included knowledge syntheses, such as integrative and systematic reviews (n = 10); commentaries (n = 2); mixed-methods studies (n = 4); quantitative studies (n = 12); and qualitative studies (n = 20). A summary of these 48 publications is displayed in Supplemental Digital Content 2, available at: <http://links.lww.com/ANS/A47>, including the country of origin of the research or publication, the design of the study or manuscript, and the health condition(s) of the care receivers under discussion. What follows is a description of the constellation of conceptual features for “informal caregiver” that we identified in the nursing literature.

### ***Attributes of “informal caregiver”***

“Role” was the essential attribute of the concept “informal caregiver.”<sup>2,6-10,13-40</sup> This role was “dyadic”: a person could not adopt the role of an informal caregiver, without another person being the receiver of his or her care.<sup>13,20,22,27,28,35,36,40</sup> However, this dyadic role was rarely described as a caregiving “partnership” between the informal caregiver and care receiver. Informal caregivers were referred to only as “partners” with the care receivers if they were the romantic partners.<sup>8,10,23,24,29,31,37</sup> This role was also “informal,” in the sense that caregivers were typically unpaid<sup>2,8,9,13,20,22,34</sup>; they were usually untrained by structured or standardized training initiatives for home care and nursing skills, instead learning complex caregiving tasks independently<sup>6,24,32,36,41</sup>; and there were no formal organizations coordinating the informal caregivers’ responsibilities.<sup>7,38,39</sup> This “informal” adjective was sometimes used to explicitly differentiate the unpaid work of informal caregivers, from the “formal” paid and trained work of other carers, such as nurses and personal support workers.<sup>7,38,39</sup> In one instance, the term “informal caregiver” included an unpaid family caregiver and a paid but untrained home care aide.<sup>42</sup> No other

articles suggested payment for the informal caregiver role.

### ***Antecedents of “informal caregiver”***

Four antecedents of “informal caregiver” were identified: (1) a pre-existing relationship, (2) a person needing care, (3) functional dependencies, and (4) a health- or aging-related condition. The pre-existing relationship emphasized emotional ties (eg, love or a desire to care),<sup>10,15,19,24,27-29,31</sup> as well as social obligations (eg, family ties and cultural values of filial piety or duty).<sup>6,19,31,37,41,43</sup> The care receivers needed assistance with activities they could not perform independently, and that formal support services were not providing.<sup>6,28,34</sup> Care receivers lived with functional “dependencies” due to a health or aging-related condition, requiring physical, mental, and/or emotional assistance from caregivers to function in their daily lives.<sup>6,7,13,14,16,21,22,28,30,43</sup>

### ***Consequences of “informal caregiver”***

Three major role consequences were identified. First, there were numerous responsibilities fulfilled by informal caregivers. Second, these responsibilities led to various health sequelae for the caregiving dyad. Third, without access to community health and social supports, these responsibilities and health sequelae often led to informal caregiver role strain and distress.

### ***Enacting numerous responsibilities to fulfill the role***

All publications listed responsibilities associated with the process of becoming an informal caregiver. These responsibilities included providing nutrition, administering medication, managing feeding tubes and central lines, performing wound care, coordinating the household, providing hygiene care, offering emotional and spiritual supports, ensuring safety, communicating with health care teams, and financially supporting the household. These tasks could be

very unpredictable, leading to derailed family schedules and unexpected stress.<sup>9,10,22,24</sup> Learning these responsibilities and their sustained enactment were at the heart of the ongoing process of becoming an informal caregiver.<sup>9,13,22,30,31,35</sup> The final responsibilities of the role involved transitioning out of the role, usually in the context of death and bereavement, with the care receiver entering hospice care or dying.<sup>29,31,36,37</sup>

### **Experiencing a myriad of health and social consequences due to the role**

The informal caregiver role had a myriad of mental and physical health consequences. Informal caregivers frequently felt mentally distressed and uncertain about their role.<sup>10,13,16,18,20,21,30,44</sup> They often suffered from physical exhaustion and lack of sleep.<sup>7,15,20,21,28-31</sup> Informal caregivers of people living with an infectious condition experienced additional mental distress due to fears of becoming ill themselves.<sup>29,31,37</sup> Some informal caregivers felt resentment, with accompanying feelings of guilt or stigma for resenting their caregiving role.<sup>6,8,21,31,37,44</sup> If informal caregivers became overburdened or experienced burnout, care receivers were more at risk for neglect and elder abuse.<sup>2,43</sup>

Dyads also experienced social consequences, particularly financial and relational. The presence of an informal caregiver reduced the likelihood the care receiver would need formal, publicly subsidized services, such as hospitalization, home care, or long-term care.<sup>13,17,19,21,25,26,34,41</sup> Hence, costs were spilled over to the informal caregiver and the care receiver, who incurred direct out-of-pocket costs (eg, paying for home care support, lost incomes)<sup>20,21,29,34,42</sup> and indirect costs (eg, time costs and career challenges).<sup>15,19,21,23</sup> Some informal caregivers had limited time to address the needs of other family members,<sup>6,31,44</sup> and many caregivers experienced social isolation.<sup>7,9,10,21,24,30,31,43,44</sup> The informal caregiver role sometimes generated feelings of self-sacrifice and identity loss.<sup>2,6,8,10,28,36,44</sup> Caregivers and care re-

ceivers often grieved their past relationship and their previous hopes for their future together.<sup>7,9,10,16,20,24,29,31,33,36</sup> However, over time and with appropriate supports, the dyads often found their relational bonds strengthened as they adjusted to their caregiving and care receiving roles.<sup>24,27,31,33</sup>

### **Needing supports to prevent role-related distress**

Most informal caregivers wanted to be their care receiver's informal caregiver, but they required support to thrive in this complex and often challenging role.<sup>6,10,19,20,30,31,36</sup> Every publication noted that without access to community health and social supports, informal caregivers were at increased risk of role strain and distress. Various supports were helpful including education and training for informal caregivers on their care receiver's health trajectory,<sup>15-18,22,24,27,32</sup> government subsidies and supplemental incomes for caregiving,<sup>15,17,44</sup> family members and friends providing substitute caregiving work,<sup>22</sup> protected leaves of absence,<sup>17</sup> and accessible respite care services.<sup>6,14,15,17,18,20-22,29,30,37,41,44</sup> When informal caregivers and their care receivers had access to adequate social and health care supports, they often experienced joy, meaning, and personal growth from their dyadic roles.<sup>10,13,17,20,21,27-31,37</sup>

Still, some authors noted that even when support services were available, these services might not have been used or requested by informal caregivers.<sup>8,17</sup> Caregivers sometimes downplayed their need for support, often due to feelings of guilt for wanting role support,<sup>8,10,21,38</sup> or to a lack of awareness of their eligibility for services.<sup>28</sup> Furthermore, available support services were often inadequate or inaccessible to many families.<sup>7,21,22,28</sup> Authors noted that efforts to optimize accessibility required codesigning supports with families and tailoring services to their unique needs, so that services were not only available but also accessible.<sup>20-22,24,27,28,32,44</sup>

### ***Contextual features of “informal caregiver”***

Four major contextual features were identified in the literature: (1) the demographic representation of informal caregivers, (2) the language of “burden” and “costs,” (3) nurses’ complex and contradictory perceptions of informal caregivers, and (4) the health care and societal contexts of the publishing period (1986-2021).

#### **The demographic representation of informal caregivers**

The representation of “informal caregiver” was highly gendered.<sup>7,8,14,20,21,29</sup> Few studies had male caregivers equally represented or as the sampled majority.<sup>27,31,37,38</sup> Immediate family members were most commonly the informal caregiver; less common were extended family, neighbors, or friends.<sup>23,29,31</sup> Informal caregivers were typically older than 40 years; informal caregivers younger than 30 years were rarely discussed.<sup>18,23</sup>

#### **The language of “burden” and “costs”**

In the nursing literature, informal caregivers were frequently viewed as a low-cost solution to the rising costs of an aging population. Authors often introduced their collective works with explicit or implicit concerns of the costly health care resources needed to support aging populations.<sup>6,7,13,16,17,19,20,22,23,35,43</sup> The “formality” and “training” language associated with the role alluded to the “costs of care” and political economic ideology in discussions of informal care. Finally, the persistent use of “burden”<sup>15,16,19,20,22,24,30,31,34,38-40</sup> suggested that informal caregivers were not receiving adequate supports. Informal caregivers and care receivers were left to “cope” with their roles,<sup>10,13,21,27,32,37</sup> without the supports that could help them find joy and growth in these roles.

#### **Nurses’ complex and contradictory perceptions of informal caregivers**

Informal caregivers were perceived by nurses in complex and contradictory ways: as

resources, as trainees, as experts, as annoyances, and as care receivers themselves. Authors of these publications noted that nurses, alongside their institutional employers, sometimes viewed informal caregivers as presumed additional resources for patient care, especially in health care systems facing limited budgets.<sup>6,7,14,25,26,34,41</sup> Simultaneously, the included nursing literature suggested that training should be afforded to informal caregivers, particularly when informal caregivers desired this service.<sup>6,10,14-16,20,22,24,25,27,28,33</sup> Acknowledging the expertise of informal caregivers, nurses sometimes advocated for informal caregivers to be viewed as essential care partners with the health care teams.<sup>6,10,20,24,26,33-37</sup> Yet, at times, nurses were said to perceive informal caregivers as annoyances to be avoided or prevented from integration within health care teams.<sup>6,22,25,26</sup> Finally, some authors noted that informal caregivers could benefit from receiving supportive nursing care alongside their care receivers, due to the negative health and social consequences that often correspond with their unsupported caregiving role.<sup>6,8,9,14,21,24,25,29,38,44</sup> As part of this care, nurses were advised to assess informal caregivers’ perceptions of support services, regularly inform them of available services, and showcase the benefits of accessing such services.<sup>22,38,39,44</sup>

#### **Health care and societal contextualities (1986-2021)**

Nurses’ understandings of the concept “informal caregiver” were embedded within the health care and societal contexts that nurses found themselves in when these manuscripts were published. The role has evolved as different conditions with different caregiving needs have emerged. From 1986 to 2021, HIV/AIDS and cancer became more chronic conditions, especially in higher-income countries; populations were aging; and many health care services were being shifted to the community. The nursing literature forecasted society’s increasing reliance on informal caregiver support with the



continuing shift of health care from hospitals to the community.<sup>7,9,14,17,21,23,26,29,31,35,36,43</sup> Concerns of the informal caregivers of HIV/AIDS patients coincided with the aftermath of the initial panic surrounding the epidemic. With time, HIV/AIDS treatments extended lives and became more widely available, necessitating ongoing informal caregiving support.<sup>29,31,37</sup> Cancer, too, was a predominant health condition requiring informal caregiving support.<sup>2,13,20,27,34-36</sup> However, since cancer frequently develops in late adulthood, the cancer literature overlapped significantly with the majority of publications that investigated informal caregiving in aging populations (see Supplemental Digital Content 2, available at: <http://links.lww.com/ANS/A47>, the table that lists all 48 publications.

### ***Surrogate and related terms for "informal caregiver"***

Surrogate terms for "informal caregiver" included "informal carer,"<sup>6,18,21,23,26,38,44</sup> "primary caregiver,"<sup>15,25,32,41</sup> and "family caregiver."<sup>35,41</sup> Use of these surrogate terms was influenced by context; for example, "informal carer" was mostly used in the United Kingdom.<sup>6,18,21,23,26,44</sup> Related terms included "parent," "partner," and "spouse." Being a "parent" was similar to being an "informal caregiver" but specifically entailed parenting one's underage or adult children who lived with complex medical conditions.<sup>18,23,31,32,34</sup> A romantic "partner" or a "spousal" role was related to but differed from an informal caregiver role.<sup>8,10,31,36</sup> Without the antecedents of a health or aging condition causing functional dependencies for the care receiver, being a "parent," "partner," or a "spouse" did not have the same meaning as being an "informal caregiver." Only when all the antecedents were met were they considered "informal caregivers."

"Provider" was another term frequently noted in the literature. A few publications used the term "service providers," referring to the people and organizations that

were paid to provide formal caregiving services.<sup>6,44</sup> Other "provider" terms included "formal care provider,"<sup>26</sup> "care provider,"<sup>15</sup> and "formal service provider"<sup>17</sup> to differentiate these formal caregivers from unpaid and untrained informal caregivers who "gave" their time, rather than "provided" their services for pay. However, a few organizations used "informal care provider"<sup>14,31,43</sup> or just "care provider"<sup>42</sup> to refer to informal caregivers, making "provider" both a surrogate and related adjective, in this literature.

## **DISCUSSION**

We performed this concept analysis to provide a deeper understanding of what "informal caregiver" means in nursing, based on a selection of nursing literature on informal caregivers. With the current attributes, antecedents, and consequences identified for the concept, the discipline of nursing can have a common foundation for understanding what the concept currently entails in our discipline. With the contextual features identified, nurses can foresee how this concept may evolve in the future. In the following sections, we discuss how these results could be used by nurses to better identify and support informal caregivers, as well as how the findings can be used to evolve nursing's understanding of the informal caregiver role toward more positive partnerships.

### **Applying this analysis to better identify and support informal caregivers**

This concept analysis offers nurses a shared understanding of the attributes and antecedents of this concept, creating a starting point for nurses to more consistently identify those who are engaged in the role of informal caregiver and to support them better. Furthermore, by recognizing that the current literature typically focuses on a certain demographic of "informal caregiver" (ie, middle-aged and older women caring for aging parents or spouses), nurses will be

equipped to question their personal assumptions about who they expect an informal caregiver to be.<sup>7,45</sup> They may ask themselves questions such as, “Am I subconsciously expecting middle-aged and older women to be more responsible for caregiving?” “Am I ignoring other relations to the patient who may also need informal caregiving resources, such as male relations and young caregivers?” “Am I forgetting about the needs of caregivers of patients with conditions less represented in the literature, such as those with conditions unrelated to aging, cancer, or HIV/AIDS; or the parents of children living with disabilities?”

By evolving toward a broader understanding of the concept, nurses can better understand informal caregivers’ diverse needs and more consistently connect them with appropriate resources, such as informal caregiver training<sup>46</sup> and respite care.<sup>47</sup> With improved understanding of the informal caregiver role, nurses will be better equipped to support informal caregivers and care receivers in their roles. Still, while it is important that nurses work to support informal caregivers who want to be their loved ones’ caregivers, it is important to recognize that not all informal caregivers willingly adopt this role.<sup>11</sup> Therefore, nurses should also be advocating for more inclusive structural supports to avoid forcing reluctant individuals into the informal caregiver role.<sup>11,14</sup>

Nurses may even be able to offer supports *before* informal caregivers identify themselves as caregivers. It can take time for informal caregivers to self-identify as “informal caregivers.”<sup>31,47</sup> However, if informal caregivers do not identify with the role, they may fail to access supportive services that specifically target informal caregivers.<sup>47</sup> Nurses may identify and help families process these role transitions and subsequently connect them with earlier support services.<sup>9</sup> By assisting informal caregivers to access caregiving supports from the outset, nurses may prevent some of the burdens associated with the role and facilitate greater personal growth.

### **Evolving the concept toward positive partnerships**

This concept analysis reveals that there is space for nurses’ understanding of the concept to evolve toward a more positive understanding of the partnerships between informal caregivers, care receivers, and nurses. This finding aligns with another concept analysis on “family caregiver-receiver mutuality,” in which the nurse authors found that the establishment of a family caregiver-receiver dyad was an antecedent for mutuality to occur, and that positive consequences of mutuality in the dyad included increased trust and fulfillment in the caring relationship.<sup>3</sup> In our analysis, the informal caregiver role was not a partnership. Informal caregivers were mostly perceived to be providing care *to* care receivers in the dyad; reciprocity in care was rarely discussed. Nurses should encourage patients and other care receivers to identify ways in which they may be offering reciprocal care in the relationship too, for example, by providing emotional support to their informal caregivers.<sup>48</sup> When informal caregivers and care receivers are treated as mutually supportive partners in care, and when they view their roles as a two-way partnership, both informal caregivers and care receivers are more likely to thrive and experience fewer role burdens.<sup>3,48,49</sup>

This concept analysis also revealed that nurses often have conflicted perceptions of the informal caregiver role, preventing true partnership from being established between nurses and informal caregivers. These complex nurse-informal caregiver dynamics are well documented.<sup>49</sup> Nurses often have reason to feel frustrated at work; when units are understaffed, and when distressed families are yelling at them, it can be exhausting for nurses to engage meaningfully with patients and informal caregivers.<sup>50</sup> Ultimately, however, perceiving informal caregivers as anything other than care partners will be counterproductive to effective nursing work and patient care.<sup>49</sup> Thus, the nursing discipline has a decision to make: nurses can

choose to keep adhering to conflicted and sometimes negative perceptions of informal caregivers, seeing them as either annoyances or resources to exploit; or, nurses can choose to focus on positive perceptions of informal caregivers. To evolve toward the latter understanding, nurses could more consistently recognize informal caregivers' role as experts on the health care team, while also acknowledging that informal caregivers may want additional training for their role, and that informal caregivers may need nursing care themselves.

Efforts to improve this nurse-informal caregiver partnership warrant a critique of the negative linguistic patterns of "burden," "informality," and "costs" noted in this concept analysis. Focusing on the "burden" of informal caregiving without addressing the underlying reasons for burden, such as lack of publicly funded and accessible support programs, does not support the caregiving dyad. Furthermore, linking "informal caregivers" with reduced budgets and cost cutting measures may undermine efforts to encourage nonexploitative partnerships among informal caregivers, care receivers, and nurses.

Finally, it is important to remember that different groups of people understand concepts differently.<sup>12</sup> Some scholars and caregiving advocates have argued that the "informal" label may lead others to misconstrue the role as being casual, unskilled, and unessential.<sup>4</sup> In our analysis, the "informal" adjective was often used strategically by nurses to differentiate the complex and unpaid work of informal caregivers from the work of formally trained and paid health care workers.<sup>7,38,39</sup> Even when nurses viewed informal caregivers as annoyances, the concept itself was never used by nurses to imply that the role was undemanding or unnecessary. Still, none of the 48 publications critically analyzed the use of the "informal" adjective for informal caregivers. If nurses choose to use the language of "informal caregiver," nurses should be prepared to defend this language choice, particularly if this concept is used in company with patients and their families.

### **Implications for nursing research**

This concept analysis has additional implications for nursing research. Van Durme et al<sup>2</sup> argued that many tools used to assess informal caregivers' experiences and needs are being developed without a clear understanding of what is meant by "informal caregiver" in the context of each study. The goal of a Rodgerian concept analysis is to "serve as a heuristic by providing the clarity necessary to create a foundation for further inquiry and development"<sup>12(p84)</sup> of knowledge relevant to the concept. Our analysis can provide an initial foundation for building better nursing measurement tools, policies, and interventions to support informal caregivers by offering nurses a shared understanding of the current use of "informal caregiver" and by directing attention toward evolutionary opportunities for the concept.

### **Limitations and future considerations**

Although our sample included nursing literature from 18 countries, 24 of the 48 publications originated from the United Kingdom and the United States. There was little discussion in these manuscripts on the effects of specific cultural traditions or socioeconomic status on the informal caregiver role. The sampled literature likely did not contain enough variation in the health conditions of care receivers to offer strong conclusions regarding potential differences between the meaning of "informal caregiver" for one type of health condition versus another. Future research to develop this concept should also more explicitly acknowledge the needs of informal caregivers who are male, who are younger, and/or who are caring for children living with complex medical conditions. Although restricting our literature sampling population to journal titles with "Nurs\*" was useful for improving the specificity of the sampled literature, the restriction likely undercut the depth of nursing-focused literature on informal caregivers, such as journals that focus on topics relevant to nursing and caregiving but that do not have "Nurs\*" in the

title. Future analyses of this evolving concept may wish to include a broader sampling population of literature, focus the sample on more specific contexts of informal caregiving, or move toward a transdisciplinary understanding of the concept.

## CONCLUSION

This concept analysis can act as a foundational guide for ongoing development of

nurses' understanding of the concept "informal caregiver." This study offers the nursing discipline a starting point to better identify and understand the needs of informal caregivers, so that nurses may improve their capacities to support informal caregivers. Thus, this analysis helps create a foundation for the structurally and conceptually sound development of knowledge, policies, and interventions necessary to support informal caregivers in the future.

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