

Care for carers: a concept analysis of support for carers of ill relatives

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Abstract

Aim: To clarify the concept 'care for carers', and enhance our understanding of caring for carers of ill relatives.

Background: Healthcare professionals often refer to 'care for carers' when discussing methods to support the carers of ill family relatives. These carers do not always receive the support they need due to a lack of clarity of the concept.

Design: A concept analysis of 'care for carers' using the Walker and Avant (2011) method.

Data source: A literature search of electronic databases and search engines, using the keywords *carer*, *caregiver*, *caring for the carer*, *caring for the caregiver*. Peer-reviewed research articles published between 2014 and 2019 and written in English language were analyzed.

Review methods: Following retrieval, research articles were analyzed to describe the uses, attributes, antecedents, consequences and empirical referents of the concept 'care for carers'. Research articles describing borderline, related, contrary and illegitimate examples were included.

Results: 'Care for carers' addresses the unique support needs of those taking care of ill family members. Carers may derive a sense of empowerment from receiving individualized and proactively rendered support.

Conclusions: Carers should be supported to develop control over their circumstances, to find meaning in their caring, to become resilient when experiencing challenges and to confirm their identity as carers of their ill relatives.

Keywords: concept analysis, clarification, care for carers, support for carers, ill relatives, healthcare system

Introduction and background

In countries with aging populations, family members often care for their relatives with long term health conditions (1). Those who care for their ill relatives become 'carers' who need the support of other family members, friends and healthcare personnel. It is thus important to conceptualize the meaning of 'care for carers'.

The global increase in people with chronic illness has caused an increase in demand for homebased care delivered by family (2). Family members may choose to care for their ill significant others rather than admitting them to institutions. Children may feel obligated to care for their aging parents (3). Many mothers feel that they know their child best and are best able to care for their children with disabilities or long term illnesses (3). Carers may also want to keep relatives in familiar circumstances (4). They want to ensure the safety and dignity of their relatives, and do not trust institutional care (5). Carers may be culturally obliged to take care of ill relatives (6).

Family members who care for relatives prefer not to be called "informal" carers because they are not substitutes for formal carers such as nurses and doctors. Family members choose to care for significant others due to pre-existing relationships (7). Typically, carers are mostly women (8), with more daughters than sons caring for aged parents (3) and more mothers than fathers caring for sick children (9). Male carers are often retired and caring for their spouse or partner, while female carers are usually middle aged, and struggling to manage care responsibilities with paid employment. Male carers also seem to use paid helpers more often than female carers who rely on respite care services (10).

In some societies, children may also care, and even be the sole carer, for their siblings and parents with diseases and disabilities. Children who are the sole carer may not want to be removed from their families and will avoid alerting authorities and support organizations about their circumstances. These children become 'unseen' carers and are not officially supported. These 'unseen' carers may be responsible for providing emotional support, physical care, tending to domestic responsibilities and even dealing with financial issues (11).

Caring for ill relatives often involves a range of tasks far beyond simple health care. Aside from daily personal care, carers may have to shop, bank and keep appointments on behalf of the ill relative and even serve as the designated power of attorney for him or her (3). Such carers have to always be available either in person or via telephone, and need to plan their own lives accordingly (12). If necessary, carers sacrifice their careers or reduce their work hours (8). Carers often feel a sense of obligation towards their ill relatives and may develop guilty feelings when the responsibility becomes overwhelming and daunting (3). Many carers of ill relatives choose not discuss the emotional and physical demands of caring and subsequently never receive support from friends, other family members or healthcare services. Carers who are comfortable asking for help may be wary of unwanted or inappropriate help. Ill relatives may also become confused if the 'help' causes change, for example, when unfamiliar people provide care (5).

Carers usually experience caregiver strain when their caring responsibilities negatively affect their physical and emotional health (14). Carers tend to neglect their own health and do not consult a healthcare provider when necessary (15). The ill relative's health becomes more important than the well-being of the carer (16). Carers who are inadequately supported may experience psychosomatic conditions (17), and caregiver strain may be exaggerated if carers are not supported by significant others (18). Caregiver strain is also intensified when carers are expected to meet the medical care needs of their ill relatives (19). In such cases, carers may feel that healthcare professionals count on them to deliver medical care, but do not "account for" them (12).

In this article, the concept 'care for carers' is analyzed to improve our understanding of caring for carers of ill relatives. Healthcare professionals often refer to the concept 'care for carers' when considering interventions to support the carers of ill family relatives. Unfortunately, carers do not always receive adequate support because the concept, and hence the needs of carers, are not fully understood.

Methodology

The Walker and Avant (2011) concept analysis method was used to select the concept; define the purpose of the concept analysis; identify the uses of the concept; determine the defining attributes of the concept; describe the borderline, related, contrary and illegitimate examples; articulate the antecedents and consequences; and define the empirical referents of the concept.

To analyze the concept of "care for carers", a literature search was conducted using electronic databases and search engines. The keywords "carer, caregiver, caring for the carer, caring for the caregiver" were used. Peer-reviewed research articles published between 2014 and 2019 and written in English language were analyzed.

Uses and definitions

According to Walker and Avant (20) all definitions and uses of the concept need to be explored and described. The following description elaborates on the uses and definitions of 'care for carers'.

According to the literature, 'care for carers' need not include major efforts, since carers do not necessarily want to stop caring for their relatives, not even for short periods. Carers value support from family members and only when that is impossible, will they turn to formal care resources, friends and community members for help. For example, many carers appreciate assistance with housekeeping chores, transport and shopping (3).

It is important that carers are not forced to accept support, but rather be introduced to formal support organizations they can access when necessary (21). In the same vein, carers' autonomy should be respected to preserve their good intentions and wellbeing. Carers who

are recognized and validated for their care of ill relatives perceive and experience more support (22). Many carers also want to be treated as members of the care team (23).

Carers' skills and abilities can be developed through training programmes aimed at their unique needs (24) throughout the caregiving trajectory (25). Although on-line programs and information to improve homebased care are easily accessible, many of these are overwhelming (26). Online information can be inaccurate and inapplicable, thus material needs to be screened and verified to prevent the use of unreliable and false information (27).

Carers should acknowledge and address their own health needs. Caring for an ill relative should not require that carers put their own lives on hold. Formal and informal organizations could offer interventions that encourage carers to protect their own physical and psychosocial health (28). Interventions might include carer support groups that provide carers opportunities to discuss common challenges in homebased care (22). Carers could interact with each other using technology, including online peer-to-peer support groups that allow carers to interact conveniently (29). Online support also includes counselling and psychotherapy. Rather than traditional face-to-face therapies, technology-based therapies could more timeously help carers to solve problems and cope with daunting caring responsibilities (30). According to Larkin, Henwood & Milne (22), telephonic consultations are an easily accessible way to care for carers.

Supporting spousal carers has added complexities. Carer-spouses generally require more alone time to recover from carer strain. Many carer-spouses also need shared activities with their ill spouse to strengthen their marital relationship (28).

Working carers appreciate support from their employers in the form of flexible employment and carer-friendly workplaces. Employers should allow carers to be contactable at work, giving carers peace of mind, allowing them to focus more effectively on their jobs (22; 2). Carers should also feel secure in their jobs. Job security should be reinforced by employment policies for work-family reconciliation. Such policies offer opportunities to share caring responsibilities between relatives, employment and government (10).

Defining attributes

The attributes of a concept refer to the most common characteristics of that concept. 'Care for carers' has the following attributes:

Care being individualized – Each carer has unique needs and requires unique support (31).

Care being offered – Carers should be informed about available support services before having to search for support (2).

Care being empowering – Carers should gain knowledge and learn new skills to care for their relatives. These skills should be transferrable to future circumstances (21).

Care being validation of contributions – Carers should be recognised and validated for caring for their ill relatives (22).

Model case

A model case illustrates the critical attributes of the concept (20). A model case of care for carers shows Nurse Thompson visiting carers and their ill relatives to offer them support from the hospice. She assesses the home care arrangements of the carers and their ill relatives and recognizes the input of the carers to the well-being of their ill relatives. Their unique needs are determined and support is rendered in an individualized and empowering manner. Debriefing and counselling are offered and peer group support enabled.

Borderline case

Borderline cases reflect many attributes of the concept but not all of them (20). For example, Nurse Thompson visits carers and their ill relatives to offer support from the hospice. She uses a self-developed questionnaire to assess their needs. Support is rendered. This case is a borderline case because Nurse Thompson rendered 'individualized care', but failed to 'recognize the input of the carer to the well-being of their ill relatives'.

Related case

Related cases are similar to a model case, but do not include all the defining attributes (20). For example, Susan often visits her neighbor, Nancy, who is looking after her ill mother. Susan feels very sorry for Nancy and assumes that her help is needed. She can't do much as she is unwell, but believes that Nancy appreciates her presence and willingness to help. Susan admires how Nancy cares for her ill mother. This related case describes the support of a neighbor, and addresses the attributes of 'recognizing the input of the carer in caring for their ill relative' and 'support being offered proactively'.

Contrary case

Contrary cases do not represent the concept of interest (20). The following contrary case describes Nurse Thompson visiting carers and their ill relatives when they apply for support at the hospice. She has vast experience with home visits and knows what care is needed. She does not waste time with an assessment, but teaches the carers how to nurse their ill relatives. She believes in standardized care. In this case none of the attributes of 'care for carers' are addressed.

Antecedents

According to Walker and Avant (20) antecedents precede the concept of interest. Before we can address the concept of 'caring for carers', we need to identify who the carers are (32). From an organizational point of view, a regional or national register of carers is required to

ensure that carers are cared for, but carers need to recognize themselves as such. Often carers of ill relatives do not perceive themselves as carers (15). Many carers believe that they are responsible for their ill relatives and do not register with official organizations. Failure to identify as carers limits support opportunities for carers, especially from formal healthcare and social service organizations (32). A potential solution would be for staff in primary healthcare settings to register carers of ill relatives, so that they can be adequately supported (21).

Many carers are unfamiliar with available support resources and do not know how to apply for financial or other forms of assistance (28), and subsequently do not use the available support. According to Willemse et al. (2), carers should be offered support and not have to ask for help. Although carers may be very willing, they may not always have the necessary skills to provide homebased care. Healthcare professionals should practice transitional care to ensure that the move from hospital to home happens with positive effect for ill relatives and carers. They need to assess if carers are willing and able to care for relatives, and any needs should be addressed (31).

Efficient caring requires that carers partner with the multi-disciplinary healthcare team (32). Carers often struggle to communicate with healthcare professionals, resulting in their needs not being identified and addressed (11). Carers should freely interact with the healthcare team, and be able to express their needs. Pilapil et al. (14) suggests that the carers and the multi-disciplinary team need to work together to identify the needs of the carers, who can then be introduced to applicable community resources. Before addressing the needs of carers, it is also important that we recognize that caring is not only a feminine activity, and that male carers should receive the same support as their female counterparts. The negative stereotyping of carers as only female, often leaves male carers without much needed support to care for their ill relatives (15).

To be beneficial, caring for carers should be planned and implemented according to the unique needs of individual carers (2; 34). Generic caring and support sources may not meet the needs of all carers. Carers' needs will depend on the disease profiles of ill relatives, all with specific challenges. These challenges may also change over time, necessitating adjustments in support (33). Planning support for carers should also consider the living arrangements of carers and ill relatives which will vary from household to household (8). The unique circumstances of carers should also play a role in the how their needs are assessed, for example, relying too much on structured assessments may result in the "voice of the carers is not being heard during carer assessments" (31). The immediate and future concerns of carers should be explored (31).

Consequences

According to Walker and Avant (20), consequences occur as a result of the identified concept. In the case of 'care for carers', the enhanced well-being of carers is the positive outcome of this concept analysis. Understanding the concept, supports opportunities for carers to learn

new skills in homebased care. Carers are also encouraged to interact with healthcare and social support services. In the post-caregiving phase, carers can improve their knowledge and skills to become employed carers of people with long term healthcare challenges. There is a growing demand for carers by patients who need care, but do not want to burden their relatives (35).

Carers who receive emotional and counselling support are more likely to adopt a positive attitude to life. Carers may feel more appreciated and develop a positive self-esteem. The caring experience can become extremely rewarding and caring can become part of the commitment to a loving relationship (28). With support, carers may feel a sense of purpose and value when caring for their ill relative (31). A positive experience may reduce the psychological distress that is often associated with long-term homebased care of ill relatives (36) and also delay the institutionalization of ill relatives (30). 'Care for carers' is associated with less carer strain (19; 37). Support for carers may reduce the mental strain caused by witnessing their relative's suffering (38). Support allows carers to find meaning in the suffering of their relatives and eases their own suffering.

The well-being of the carer and the care provided are both enhanced when the carer is supported by family, friends and healthcare services. This is especially true for parents who are caring for their children and have to maintain an optimal home environment for everyone. With sufficient support, parents can care for their ill or disabled child without neglecting their other children or their own well-being (39).

'Care for carers' prolongs the care of ill relatives at home. If carers are under strain, there may be an increased risk of the patient being admitted to hospital (1). Caring for the carer allows carers stay healthy and to continue caring for their ill relatives at home (28; 9).

Empirical referents

Referents are observable indicators that the concept is real (20). In the concept analysis of 'care for carers' the following referents are observed:

Carers are in control. Carers who are supported are in control of their own daily life and the care of the ill relative. Although carers do not know what may happen in the future, support allows them have control over daily challenges (5).

Carers are resilient. Resilient carers are positive about their responsibilities and maintain their relationships with their ill relative. Resilient carers are supported by family, friends and support services (40).

Carers find meaning in caring. Most carers experience caring as right and fair. They may not have chosen the responsibility, but "it feels right within the context of the cycles of their own life" (41). With support and love, these carers are not resentful of the sacrifice made when caring for their ill relatives (41).

Carers confirm their self-identity. Carers who are at peace with caring for their ill relatives see themselves as carers. Their identity of being a carer fits with their sense of self. They value support and help from others and are proud of how they perform their caring duties (41).

Illegitimate case

In an illegitimate case the concept 'care of carers' is used out of context (20). For example, 'care of carers' does not apply to nurses taking care of one another in demanding patient situations.

Conclusion

Carers of ill relatives require extensive support from others. Healthcare practitioners should view them as valuable contributors to the well-being of the patient. Carers benefit from individualized empowering support to develop control over their circumstances, to find meaning in their caring, to become resilient when dealing with challenges and to confirm their identity as carers of their ill relatives.

Limitation of the study

Socio-cultural factors that may influence 'care for carers' were not discussed. Cultural groups differ in defining care, carer and ill relative. Further research to analyze it is therefore recommended.

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