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The meaning of care dependency as shared by care givers and care recipients: a concept analysis

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Abstract

Title. The meaning of care dependency as shared by care givers and care recipients: a concept analysis

Aim. This paper is a report of a concept analysis to identify a meaning of care dependency that can be shared by both care givers and care recipients.

Background. Care dependency can be perceived from the care recipient's and the care giver's perspective. To allow for comparisons, both sides should share the same understanding of the concept. The current research about care dependency has focused on external assessment by nurses and suffers from a tendency to use the concept with different meanings. As a consequence, research on dependency may capture different phenomena.

Method. Walker and Avant's method for concept analysis served as the guideline for this study. The Medline, CINAHL and Cochrane databases were searched for the period 1996–2006 using the terms dependence, dependency, care dependence and care dependency.

Results. Care dependency can be defined as a subjective, secondary need for support in the domain of care to compensate a self-care deficit. Functional limitations are a necessary antecedent and unmet needs are a possible consequence of care dependency. The conceptual difference between care dependency, functional limitations and unmet needs may be meaningless for study participants. They may better understand these differences if they are asked about all three phenomena in the same investigation.

Conclusion. Care givers and care recipients can agree on the suggested attributes of care dependency but may judge them in different ways. Self-assessed care dependency has the potential to challenge preconceptions of care givers about care dependency.

Keywords: care dependency, care givers, care recipients, concept analysis, functional limitations, nursing, self-care deficit, unmet needs

Introduction

Care dependency is a common topic in the current nursing literature. Studies in several industrialized countries such as Sweden (Sonn 1996), the Netherlands (Dijkstra 1998) and Japan (Ho *et al.* 2002) have been performed to investigate this phenomenon, and other research indicates its growing importance in developing countries as well (Jitanpukul *et al.* 1993; Boggatz & Dassen 2005). At the same time, several instruments have been developed which claim to measure care dependency (Edwardson & Nardone 1996, Endacott & Chellel 1996, Dijkstra 1998). A closer look at such papers, however, reveals that the concept is used with different meanings. Functional limitations (Challis *et al.* 2000), needs (Dijkstra 1998) or staff workload (Adomat & Hewison 2004) appear to be synonyms of care dependency. Other authors describe care dependency as a disadvantageous condition implying powerlessness and unmet needs (Ellefsen 2002). Such findings create confusion and raise the question of which phenomenon is being investigated in research on care dependency.

Background

The notion of care dependency is implied in the theoretical work of Orem (2001). She distinguishes between self-care as the 'activities that individuals initiate and perform on their own behalf in maintaining life, health and well-being' (Orem 2001, p. 43) and dependent care as the 'activities that responsible... persons initiate and perform on behalf of socially dependent persons' (Orem 2001, p. 515) who have limited, health-associated abilities to meet their self-care demands. Dependent care is thus a response by a care giver to a mismatch between particular abilities and needs of a care recipient who, as a logical consequence, can be described as care-dependent. The studies cited above all refer to this broad understanding of care dependency and indicate that the concept itself needs further clarification.

Another problem, not explicitly addressed by Orem, concerns the question of who will determine that someone is care-dependent. Quite often, care dependency is estimated from the care giver's perspective. If nursing is interested in patient autonomy and participatory decision-making, it would be useful to have an idea of care recipients' point of view. Would they describe and assess their situation as professional care givers do? An answer can be found in a comparison of self-reports and external assessment by nurses or nursing assistants. This requires an understanding of the concept shared by care givers and

care recipients. If they do not speak the same language, they may talk about different phenomena. A concept analysis might help to differentiate care dependency from related but not identical concepts, and to determine the meaning of care dependency that is relevant for both care givers and care recipients.

Such a shared understanding does not preclude differences in perceptions of the phenomenon. Care providers may perceive care dependency as a burdensome responsibility (Strandberg & Janson 2003), whereas care recipients may experience it as struggle to get care (Strandberg *et al.* 2003). Nevertheless, there should be a common understanding about what each side is either responsible or struggling for.

Aim

The aim of this concept analysis was to identify a meaning of care dependency that can be shared by both care givers and care recipients.

Method

Concept analysis method

The concept analysis methods proposed by Walker and Avant (2005) served as a guideline for this study. This requires the following steps:

- select a concept,
- determine the purpose of analysis,
- identify all uses of the concept,
- determine the defining attributes,
- construct model, related, unclear and contrary cases,
- identify antecedents and consequences of the concept, and
- define the concept's empirical referents.

Search methods

The current use of the term care dependency was identified in two steps.

First, the general meaning of dependency and its different ways of use in common language were identified using online editions of the *Compact Oxford English Dictionary* and *Webster's Dictionary*. Because of the increasing importance of the internet in present-day communication, *Wikipedia* as an online dictionary created by users of the internet was also searched.

Secondly, to identify the specific use of care dependency in the health sciences, a search was performed in the databases Medline, CINAHL and Cochrane. Search terms

were 'dependence', 'dependency', 'care dependence' and 'care dependency'.

Additional literature was retrieved by contacting experts in care dependency research. Three kinds of papers were included for further evaluation: (1) those that included a theoretical discussion about the concept 'care dependency' or 'dependency' in general, (2) qualitative nursing research that attempted to understand the phenomenon of dependency from either the care givers' or the care recipients' perspective and (3) nursing research that claimed to measure care dependency, as the instruments used in such research imply a particular understanding of this concept.

To cover various aspects of care dependency, care recipients were defined as people receiving nursing care regardless of age, health problem or institutional setting. The initial analysis was restricted to articles published from 1996 to 2006. To obtain a broader spectrum of ideas, this time frame was extended in a later step and older publications (from 1976 to 1996) were included if they provided additional information.

Data analysis

To identify the defining attributes, different aspects and meanings of care dependency were extracted and categorized. A simple list of identified meanings, however, might yield inconsistent attributes. For this reason, the identified categories were compared with each other to determine their consistency and possible contradictions. The arguments in favour and against each attribute are presented below. After a careful consideration of each finding, a definition was derived from the consistent categories; this then led to the defining attributes of the concept. This approach allowed determining antecedents and consequences simultaneously. As Walker and Avant point out, their method does not require step-by-step implementation.

Results

Care dependency is a particular form of dependency. It thus shares the defining attributes of dependency and its meaning is specified in relation to care. Four general meanings and aspects of dependency were identified: restricted ability to do without, relying on someone for support, abnormal condition and subjective perspective. Five further meanings and aspects of care dependency in particular were found in the literature: functional limitations, need, self-care deficit, nature of support required and unmet needs.

General meanings and aspects of dependency

Restricted ability to do without

According to *Webster's Online Dictionary* (2006), dependency means a lack of independence or self-sufficiency. The *Compact Oxford English Dictionary* (2006) describes dependency as a state of being dependent, which is defined in its broadest sense as being 'contingent on or determined by' or as 'being unable to do without'. This broad meaning is reflected in a variety of uses in different disciplines. In computer science, dependency is the degree to which each program module relies on each other module (*Wikipedia* 2006). As a grammatical term, the meaning of dependent is being 'subordinate to another clause, phrase or word' (*Compact Oxford English Dictionary* 2006). In the social sciences, so-called dependency theory suggests that the wealthy nations of the world need a peripheral group of poorer states to remain wealthy (*Wikipedia* 2006). In a political sense, a dependency describes a country or province controlled by another (*Compact Oxford English Dictionary* 2006). What all these examples have in common is that they describe a relationship between objects or people in which someone or something has an at least restricted ability to do or be without someone or something else to achieve a desired state or function. In this sense, an appropriate use of the term would be the statement that human beings are dependent on water or oxygen for their survival. In some cases, as can be seen from the example of dependency theory, such a relationship implies disadvantages for one side.

Relying on someone for support

A further meaning given by the *Compact Oxford English Dictionary* (2006) describes a certain kind of such dependency relationships as 'relying on someone or something for financial or other support'. George (1991, p. 178) restricts this meaning further to social relationships when he writes, 'one cannot simply be dependent; one must be dependent on someone for something'. This kind of dependency has three components: two social actors and a support to which they refer. It can occur at a macro-level, for example, in the case of development aid where one country relies on financial support from another, or at a micro-level between two individuals. Clearly, care dependency, which implies such a relationship, falls into this latter subcategory.

Abnormal condition

A further aspect of dependency can be found in expressions such as drug or tobacco dependency. According to *Webster's Online Dictionary*, this kind of dependency means 'being abnormally dependent on something that is psychologically

or physically habit-forming'. According to this description, the restricted ability to do or be without something appears to be just felt, without a necessary reason. Although smokers may believe that they cannot quit cigarettes and experience discomfort if they try, there is no evidence that they would experience serious physical consequences because of the lack of nicotine. The same would not be true if they tried to survive without water. Some kinds of dependency therefore seem to be avoidable and others not.

The same may be the case if individuals feel that they have to rely on support from someone else. According to the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association 2000), they may suffer from a dependent personality disorder, which is characterized by a pervasive and excessive need to be taken care of that leads to submissive and clinging behaviour and fears of separation. As the well-being of affected people might improve without this felt dependency, their condition is similar to drug or tobacco dependency.

Subjective perspective

The difference between avoidable and unavoidable dependency is, however, in most cases not so obvious. According to Van den Heuvel (1976), dependency arises whenever individuals define their situation as dependent or if someone in the individual's environment does so. Without such a subjective definition, there would be no dependency at all. As a consequence of this subjectivity, any statement about dependency may be disputable. This concerns the perspective of both sides. Comparisons between the assessments of care recipients and professional care givers, for example, have shown that professionals identify more dependency than their clients (Morrow-Howell et al. 2001, Hansen et al. 2002). Such discrepancies raise, of course, the question of whose judgement is more appropriate. A comparison of such judgements with an external criterion could to some extent offer a solution. Dijkstra (1998), for example, found that patients with severe dependency (as assessed by nurses) had a 20% higher mortality than expected for the general population of the same age. If self-assessments by patients were included in such a study, we could determine their predictive value and compare it with the judgements of nurses. A mere survival rate, however, does not tell us anything about the care recipients' quality of life, which may require dependency on others to be maintained. Self-reports have the potential to challenge external assessments by nurses, which are not necessarily the better ones. In some cases, self-perceived dependency may reflect an avoidable condition in the sense of a dependent personality disorder, but this is unlikely to be the case in the majority of care recipients. If dependency is a

subjectively-felt condition, this does not imply that such perceptions have in general a pathological nature. For this reason, abnormality should not be considered as a defining attribute of dependency.

Particular meaning of care dependency

If care dependency is a kind of social support relationship that can be perceived from the perspective of both sides involved, we now have to define its particular content to differentiate it from other kinds of support relationships. Figure 1 shows the relationship between the defining attributes which are discussed in the following.

Functional limitations

Several of the retrieved studies appeared under the heading of care dependency and used this term as a synonym of functional limitations (Iwarson & Isacson 1997, Challis et al. 2000, Ho et al. 2002). Functional limitations are a reduced or missing ability to perform a particular task considered necessary for daily living (Pearson 2000). In a similar way, the *International Classification of Functioning, Disability and Health* (ICF) defines activity limitations as difficulties in the performance of a task or action by an individual (World Health Organization (WHO) 2001). These activity limitations may concern a wide range of domains from self-care to community, social and civic life. They thus have an impact on all biopsychosocial dimensions

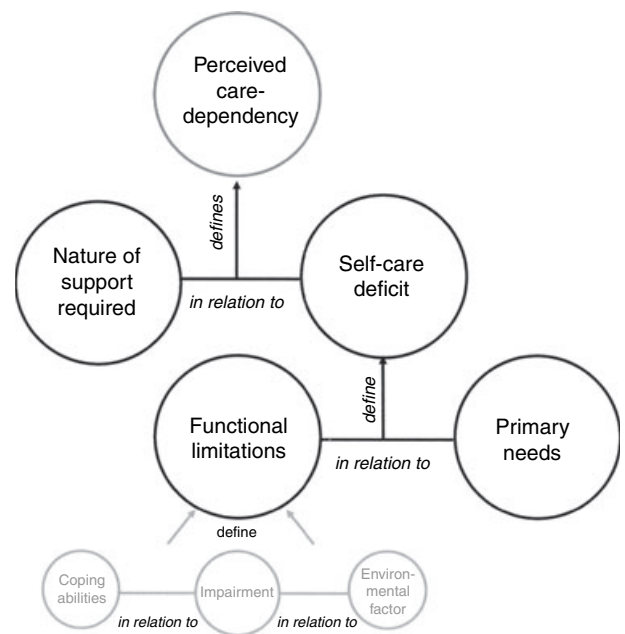


Figure 1 Attributes of care dependency.

of human life. There is an agreement that such limitations cannot be equated with impairments. According to the ICF, impairments are problems in body function or structure, such as a significant deviation or loss (WHO 2001, p. 12). The loss of limbs or limited ranges of motion are the examples of impairments. Activity limitations are associated to impairments but they reflect more than this concept. The ICF points to the influence of environmental factors on task performance by introducing a difference between capacity and performance. Whereas capacity describes an individual's ability to execute a task in a 'standardized' environment that neutralizes the varying impact of different environments, performance refers to what an individual does in their current environment (WHO 2001, p. 15). For example, individual people with impaired mobility may experience problems in toileting because of impediments in the bathroom, or they may be unable to go shopping as there is no elevator. If there are no such restraints, they may even perform above their capacity.

Another factor that contributes to a functional limitation is the person's coping abilities. People may vary in their degree of ability to adapt to physical impairment. In a case study of a low-income Egyptian hamlet, Lane *et al.* (1993) described visually impaired individuals who remained functionally independent. They were leaving the hamlet, taking crowded buses and the authors claimed that one even drove a motorbike. Thus, functional limitations are a function of impairments, environmental conditions and coping abilities.

Need

Several authors (for example, Cignac & Cott 1998, Wilkin 1987) criticize the equation of functional limitations with dependency. They point to the fact that someone may reduce a need for a particular activity to remain independent. If individuals with a reduced ability to walk are less inclined to leave their houses they will feel a lower need for this activity than someone else who maintains this desire. Needs for task performance may, furthermore, depend on the particular demands of social roles. Impaired mobility will be experienced quite differently by an office worker and a manual worker. Thus, functional limitations do not necessarily produce care dependency. There is some empirical support for this study. In an analysis of cross-sectional data, Desai *et al.* (2001) found that < 50% of older people reporting a functional limitation expressed a need for help.

If needs are implied in care dependency, a closer examination of this concept is required. Endacott (1997, p. 474) provides us with a concept analysis of needs where she comes to the conclusion that the defining attributes are: 'an undesirable state of affairs, a deficit, a necessity, its presence

confers responsibility to make good the deficit, and evaluative notion (or value judgement): someone has to define them as needs'. Maslow's notion of needs may be added to this description. He saw them as a drive of human behaviour that aims to avoid deficits (Maslow 1943). According to him, needs are permanently operating in human beings and do not just appear if there is a functional limitation. The needs are, furthermore, not static. They change over time and according to circumstances. As they are operating inside people they also have a subjective aspect, which is recognized by Endacott as she considers an evaluative notion as an attribute of needs. Older people, for example, may feel no need to drink despite a risk of dehydration. Whether care recipients describe their situation as an undesirable state of affairs and a deficit will thus depend on a subjective drive or motivation that produces an evaluative notion about this situation. To avoid conceptual confusion, we suggest calling the subjective drive or motivation the care recipient's need, and the evaluative notion, which describes a certain state of affairs as undesirable, the perceived deficit. If care givers and care recipients disagree about such a deficit, it is likely that care recipients do not feel a subjective need whereas care givers assume that they have or should have this need.

Self-care deficit

If we combine the two previous considerations, we have to conclude that functional limitations are just an antecedent to care dependency. To feel care dependent requires in addition a perceived need which is affected by this functional limitation. This interpretation is in line with Orem's (2001) theory of self-care deficit. She defines self-care deficit as a relationship between self-care agency, which is an equivalent to functional abilities or limitations, and self-care demands, which are an equivalent to needs. It is thus more appropriate to say that self-care deficit, as a relation between activity limitations and needs in all biopsychosocial dimensions, is a defining attribute of care dependency.

According to Orem (2001), a self-care deficit requires compensative actions by nurses or care givers. These compensative actions respond to needs, which are normally satisfied by self-care activities. They are simply a substitute which would not be necessary if the person did not suffer from functional limitations. Healthy persons do not need care; they need food, safety, social acknowledgement and so on. These kinds of needs should be called primary needs. In contrast, a perceived need for support is a derived or secondary need. Self-perceived care dependency thus means a subjective, secondary need for support to compensate a perceived self-care deficit.

Nature of support required

Any support has to be perceived as adequate to meet a felt self-care deficit. A judgement about care dependency therefore implies an idea about the nature of support that should be provided, and this nature has several aspects. First, care recipients and care givers have to decide about the domains of dependency. According to Wilkin (1987) and Cignac and Cott (1998), dependency can be divided into different domains such as personal care, household tasks, community mobility etc., and each of these domains can be divided further into subcategories. Not all these domains may be perceived as belonging to the responsibilities or abilities of care givers. Ideas about tasks of care may vary from person to person. It is possible that care recipients feel a need for support which care givers perceive outside the realm of their responsibilities, or that care givers want to provide a service which care recipients do not consider to be a care giver's task. An assessment of care dependency from both sides should therefore be based on a commonly-accepted agreement about the domains of care. Such agreements may be different from culture to culture. For example, care givers in a Christian elder care home in Upper Egypt felt that religious support was an important part of their care (Boggatz & Dassen 2006). However, this aspect may be missing in countries where people are less religious or have different spiritual needs. The assessment of care dependency in a particular culture thus requires identifying domains that are relevant for care in this culture.

Assessments of every identified domain will show different degrees of dependency. Some measurements of care dependency attempt to capture this aspect by equating it with the workload of care givers. Care dependency would then be the time needed to satisfy a need for supportive actions which could be assessed from both the care giver's and care recipient's perspective. Workload measures, however, should capture also indirect nursing care such as care planning, checking equipment or communication among team members if they are to be adequate (Williams & Crouch 2006). Workload as a concept is therefore more than dependency on supportive care actions.

Even if workload measurement was restricted to direct supportive actions, such an approach would remain problematic. George (1991) gives the example of patients with self-care deficit in feeding who can be encouraged to feed themselves or can be spoon-fed. Which option is chosen depends on implicit goals that determine the perceived requirement of care. Such goals can be different for care givers and care recipients. Dijkstra (1998) perceives care dependency as a support with the aim of restoring a patient's independence, and a care giver should rate the care recipient

as less dependent on direct support and choose a time intensive encouragement. Baltes (1995) describes cases where people preferred some dependency, as delegating certain tasks helped them to free energies for other activities of higher priority. She called this phenomenon 'selective optimization with compensation'. To find compensatory assistance, such people might express a higher need for direct support in some domains. The degree of dependency that is perceived by care givers or care recipients may thus depend on different goals that each side pursues in the care process.

Unmet needs

As care dependency can be perceived from such contrary perspectives, previous authors have come to different conclusions about the character of dependency relationships. According to Van den Heuvel (1976, p. 165), dependency means that 'the individual sees his situation negatively; the environment does not recognize this situation in the same way.' Care dependency would then be characterized by the fact that someone feels a need for care but does not receive it, and self-reports would express unmet or under-met needs. There is some empirical support for this study. Some authors (Nordgren & Fridlund 2001, Ellefsen 2002, Strandberg *et al.* 2003) have come to the conclusion that the meaning of dependency from the care recipient's perspective is associated with constraints, loss of freedom and powerlessness.

In contrast, Cignac and Cott (1998) define dependency as a relationship in which someone receives care regardless of whether they need it or not. Care givers may even impose their support and make the person more dependent. According to their terminology, someone with unmet needs is classified as 'not independent'. To solve this terminological dispute, we must be clear about the fact that perceived care dependency is not identical with the dependency relationship itself. It is only a judgement about how this relationship should be, either from the care recipient's or care giver's perspective. If care recipients feel that they should receive support, people in their environment may agree and satisfy the felt need or disagree and cause unmet needs. If care recipients do not feel a need for support, people in their environment may impose help or agree and leave them independent. Unmet needs are therefore just one possible consequence of self-perceived care dependency and should be differentiated from this concept, even if empirically these phenomena show a strong association.

In summary, perceived care dependency is a subjective assessment about a social relationship, i.e. about the extent of having a secondary need for a particular kind of support called care to compensate a perceived self-care deficit. An assessment of care dependency will thus reflect the kind and

extent of support a care recipient should receive, either from their own or from the care giver's perspective. Both assessments will refer to the same components of care dependency (functional limitations, needs and nature of support required), but they may judge them in a different way (for example, the care giver may assume a higher need for mobility than the care recipient).

Model, related, unclear and contradictory cases

A model case would be an older man with impaired mobility, living in a residential care home, who feels the need to receive support from a nurse with daily hygiene as he considers this to be important for his well-being and the provided help as a relief from strain. A related case would be the same resident who does not receive the complete degree of desired care because of time limitations of staff members. Such a person should be classified as care dependent with unmet needs. An unclear case would be residents of a nursing home with impaired mobility who feel a need for hygiene assistance but who are reluctant to accept care as, according to their culture, this should be provided by relatives or a care giver of the same sex who is not available in the setting. Such residents might change their opinions if there was an option to receive culturally adequate care. A contradictory case would be older people with impaired mobility who have learned to manage their disabilities by using assistive devices, and who strive to remain independent even if this implies certain limitations on their range of mobility.

Empirical referents

As care dependency is a subjective condition, statements of care recipients about the felt need of care are the only suitable way to capture this phenomenon. The care givers' statements will describe the same situation, but they cannot reflect the care recipient's point of view. The same concerns observation of care provided. An institutional setting may impose some kind of support as it is more time-saving in comparison with allowing independent performance of a task. As described above, assessments of functional limitations or workload will also not exactly reflect the nature of the care dependency.

To allow comparisons with care givers' perceptions, care dependency should be specified in a way which is acceptable to both sides. In an attempt to capture care dependency from the care giver's perspective, Dijkstra (1998) developed the Care Dependency Scale. Its items are related to basic human needs as described in the nursing theory of Henderson (1991), and ask about degrees of required care.

This approach also seems to be suitable to capture self-perceived care dependency. It simply requires a self-assessment version of the same instrument, which has recently become available (Dijkstra *et al.* 2006). Application of this instrument in cultures different from the Netherlands, for which it was developed, will require conceptual and item equivalence to be established (Streiner & Norman 2003) as not all the domains of the original conceptualization may exist in the target culture and the wording of items may be inappropriate.

Discussion

The main objection that can be raised against the suggested conceptualization of care dependency is that the differences between functional limitations, care dependency and unmet needs are of a rather academic nature. The study participants may not be aware of such conceptual subtleties and may perceive these concepts as interchangeable with each other. In the lives of care recipients a functional limitation may simply be a synonym for a felt need of care, and care dependency may mean to be powerless and disadvantaged. Why, then, should research introduce such differences, if they are meaningless to care recipients? Clearly, any research results will depend on what researchers want to know and the kinds of questions they ask. For this reason, researchers should be clear about the meaning of the concept they want to investigate. Whether study participants will share their conceptual differences will depend on how clearly researchers formulate their questions. To avoid possible misunderstandings, questions could focus on functional limitations (what are you able to do?), care dependency (how much support do you need?) and unmet needs (do you get this support?) in the same investigation. In this way, the difference between the three concepts will become clear to the participants.

Furthermore, two concepts commonly associated with care dependency were excluded from the definition. Functional limitations are a necessary antecedent and unmet needs are a possible consequence of care dependency. Such a differentiation is crucial. On the one hand, it clarifies that care dependency is not by nature a negative state. People can be dependent on their care givers but may remain satisfied and in control of the situation provided their needs are met. On the other hand, it prevents care givers from assuming that functional limitations equate with a need for support which may cause them to neglect the resources of self-support among care recipients and to impose supportive actions. Baltes (1995) gives evidence that at least to a certain extent care dependency is learned through dependence-supportive

What is already known about this topic

- The concept of care dependency is implied in the theoretical work of Orem.
- Research into care dependency is mainly based on a care giver's perspective and has used functional limitations and nursing intensity as empirical referents of this concept.
- Studies exploring care dependency from a care recipient's perspective have identified constraints, loss of freedom and powerlessness as characteristics.

What this paper adds

- Care dependency is defined as a need for support in at least one domain of care to compensate for a self-care deficit.
- Domains of care need to be agreed upon by care recipients and care givers and may vary to some extent between cultures.
- Functional limitations and unmet needs are related but not similar concepts of care dependency.

behaviour by care givers. Asking care recipients themselves about their perceived need for support has the potential to challenge such preconceptions and may cause care givers to rethink their practices.

Conclusion

The concept analysis has allowed components of care dependency to be identified upon which both sides can agree. These components should thus become the defining attributes of the concept. If these attributes are put together in a short definition, care dependency is a subjective, secondary need for support in the domain of care to compensate a self-care deficit. Care givers and care recipients will both refer to these attributes while talking about care dependency, but each side may assess them in a different way. The definition therefore allows different perceptions of the same phenomenon.

Author contributions

TB was responsible for the study conception and design and the drafting of the manuscript. TB performed the data collection and data analysis. AD and CL provided administrative support. AD, CL and TD made critical revisions to the paper. AD and TD supervised the study.

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