

## Chapter II

### **Manuscript 1—A Concept Analysis of Children's Agency Within the Health Literature**

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Supplementary File 2 (published online) includes the summary of the characteristics of the articles included in the concept analysis, categorized by trends, which is in Appendix B to this thesis.

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### Abstract

The capacity of children to act as agents is being increasingly recognized and has important implications for health research and practice. However, there are various discrepancies in how children's agency is defined in the literature. The aim of this analysis was to examine the concept of children's agency within the health-related literature, using Rodgers evolutionary method. The following questions were addressed: (a) How did the concept of agency become associated with children in the health-related literature?; (b) What are the sociocultural and legal contexts that surround the concept of children's agency?; (c) What is the meaning of children's agency? A total of 45 articles were included in the analysis. An inductive approach was used to identify the attributes of children's agency, as well as the temporal, disciplinary, and paradigmatic trends in its conceptualization. The concept of children's agency first appeared in the health literature in the 1980s, and was defined as an ability children could gradually develop. Later on, children's agency was used to refer to the capacity of all children to influence their own and others' health care needs, and is now increasingly used to refer to children as active agents who reflect on and construct their social worlds.

*Keywords:* Agency, agent, child, concept analysis, health, pediatric, Rodgers evolutionary method

## A Concept Analysis of Children's Agency Within the Health Literature

Since the 1970s, the idea of children as having agency is increasingly discussed in the research literature, particularly in the interdisciplinary field of childhood studies (James, 2009). From an ethical standpoint, agency is often presented in direct opposition to the best interests standard, in that children are considered in need of protective measures in their best interests, until they gain the capacity to act as agents. Recently, the need to reconcile these views in favor of a framework in which children's agency and best interests can both be recognized and coexist has been put forward (Carnevale et al., 2015). From this perspective, children are perceived as having highly varied agential capacities, which should result in a broad conception of children's agency that recognizes this wide range of agential capacities.

This article places itself in this context, aiming to clarify the concept of children's agency specifically in the health-related literature. A significant body of literature has examined and developed agency in childhood (for example in philosophy and the social sciences), but this concept has not been clearly articulated in relation to children within the health literature. This lack of conceptual clarity has important implications in a health context, as the way children's agency is conceptualized will have important implications for how health care will be decided upon and provided, as well as deeply affect how health research will be designed and conducted. Clarifying the characteristics of children's agency and retracing its evolution can contribute to the knowledge development process for this concept, by improving communication among users of the concept, as well as providing a conceptual foundation on which further inquiry could be based.

This analysis sought to explore how children's agency is conceptualized in the health-related literature from an evolutionary perspective. The following questions guided the analysis:

(1) How did the concept of agency become associated with children in the health-related literature?; (2) What are the sociocultural and legal contexts that surround the concept of children's agency?; (3) What is the meaning of children's agency?

### **Rodgers Evolutionary Method**

The method used in this concept analysis is based on an evolutionary view developed by Rodgers (2000), which is mainly grounded in the philosophical views of Toulmin and Wittgenstein. Following this philosophy, concepts are perceived as being dynamic in that they do not remain stable over time and context, but “change, grow, and develop (and need to be developed) in an evolutionary manner” (Rodgers, 2000, p. 100). Using this method is not expected to result in a finite, universal definition of the concept, but rather to clarify the attributes of the concept in order to promote its understanding and facilitate communication.

### **Data Sources**

#### **Concept of Interest**

Children's agency is the concept of interest for this analysis. The term *children* is used here to refer to minors from 0 to the age of majority, which is usually defined as 18 years old (United Nations Convention on the Rights of the Child [UNCRC], 1989). The term *agency* has multiple usages, and is usually employed in the social sciences to refer to self-determination or the ability to act independently (O'Leary, 2007). In this analysis, the focus is on agency as it relates to humans—specifically children—as agents who have the capacity to act (Carnevale et al., 2015).

#### **Setting and Sample for Data Collection**

The time period examined for this concept analysis ranges from 1951 to 2014, to analyze the development of the concept over time. Since the focus of this analysis is on children's agency

within the health-related literature, articles from multiple fields were screened for potential inclusion in the analysis, with no limitation regarding the disciplinary orientation of the authors or journals, as long as the article was related to health. Health is a highly multi- and interdisciplinary field, and the selection of specific disciplines could have discarded important views on the concept (Rodgers, 2000). Searches were performed using CINAHL (Cumulative Index of Nursing and Allied Health Literature) and PubMed (free access version of MEDLINE), which are the two primary computerized databases indexing health-related literature.

The searches combined yielded a total of 2901 articles, from which 45 were retained for inclusion in the analysis (see Supplementary File 1 for the details regarding databases searches).

*Supplementary File 1. Details regarding databases searches*

Search terms <sup>19</sup>	Total number of articles	Number of articles retained
agen* or autonom* and child* in title <sup>20</sup>	2582	36
adolesc* or autonom* and child* in title	291	9
self-determination and child* or adolesc* in title	18	0

Duplicates were first removed, and titles and abstracts were screened for relevance to the present concept analysis: articles related to a pharmacological *agent* or institutional *agency*, were by far the most prevalent and have not been retained. Conference abstracts and book reviews were also excluded, since these writings did not provide an elaborate enough view of the concept. In accordance with Rodgers' concept analysis method (2000), additional searches were performed while analysing the initial articles to include surrogate and related terms (e.g.: adolesc\* and self-determination). Considering the multiple usages of the words agency and agent, identifying the

<sup>19</sup> All the searches were performed in November 2014, and were limited to the French and English literature.

<sup>20</sup> The concept of autonomy had been identified as a possible surrogate term for agency (Carnevale et al., 2015), and was thus included in the initial searches performed.

relevant literature was quite challenging. Olli et al. (2012) have also highlighted this difficulty in their review of factors affecting agency in children with disabilities: through different computerized searches in seven databases yielding abundant results, they could identify only two articles of relevance to their study.

### **Data Management and Collection**

Each text was first read in full to “identify the general tone of the work and to gain a sense of the writer’s use of the concept” (Rodgers, 2000, p. 93). The following questions were asked for each text and recorded on an Excel worksheet: (a) Why was this document published?; (b) How does it relate to children’s agency?; (c) What are the surrogate and related terms that are used?; and (d) How is children’s agency defined? In addition to these questions, the year of publication and the primary author’s disciplinary and country affiliations were recorded to allow a comparative analysis based on these contextual criteria. A second reading of each article was then performed, in order to identify and organize the data into the three specific categories: attributes, contextual basis, and references (see Supplementary File 2 for more details related to data collection, which can be found in Appendix B to this thesis).

In addition to the Excel worksheet, a record was kept of the researchers’ thoughts and perceptions throughout the analysis process. This document was used to help the researchers identify major themes and keep track of the analytic process. This also provides an audit trail that can be used to retrace the steps of the analysis, contributing to the credibility of the inquiry (Rodgers, 2000).

### **Data Analysis**

An inductive analysis was conducted to identify the different themes related to the three categories: attributes of children’s agency, contextual basis, and references. As suggested by

Rodgers, labels were first identified, followed by an exploration of areas of agreement and disagreement in how children's agency is conceptualized, looking at disciplinary, temporal, and paradigmatic trends. Rodgers does not mention specifically the analysis of paradigmatic trends, but mentions that concepts may be viewed through various contextual bases. The framework used to analyze the paradigmatic orientation is the one developed by Lincoln and Guba (2000), who identified five paradigms labeled as: positivism, postpositivism, critical theory, constructivism, and participatory. The paradigmatic analysis was valuable in highlighting the perspective from which the research was conducted, and related view of children and childhood (e.g.: the child as the object of research in positivism).

## **Results**

The data was grouped to emphasize the trends in how the concept of children's agency has evolved over time in the health literature, to provide greater insight into the contextual elements that contributed to its development (Rodgers, 2000). The distinctive attributes of the concept are based on the temporal, disciplinary, and paradigmatic analyses<sup>21</sup>.

### **Appearance of the Concept within the Health Literature: Orem's Self-care Agency**

The concept of agency in children within the health literature first appeared in the late 1980's in the American nursing literature, with different articles being published referring to Orem's self-care theory as their main framework<sup>22</sup>. In Orem's theory, each person is considered as a self-care agent. Self-care agency is defined as one's ability to engage in self-care in order to enhance treatment and prevent illness (Orem, 1976). However, in Orem's initial theoretical framework, self-care agency did not apply to children; parents and other adults were considered

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<sup>21</sup> Due to space limitations, not all the references are included here. Please refer to Supplementary File 2 for descriptions of the characteristics of the articles included in the concept analysis, as well as a complete listing of the references.

<sup>22</sup> No articles were identified that referred to children's agency prior to the 1980s, despite the inclusion of articles from 1951 to 2014 in the literature searches.

to be fully responsible for children's self-care. This view was present in a study by Gaffney and Moore (1996), in which adults were considered the "dependent care agents" for children who were described as having no self-care agency.

In order to apply Orem's self-care theory to children, different authors provided an altered view of agency that was related to children's developmental abilities: they assumed that there is a transition process in which children progressively acquire a greater ability to perform self-care agency. Children were referred to in these articles as the recipients of care, who were slowly *becoming* self-care agents as they moved into adulthood.

### **Developmental Perspective**

From the beginning of the years 2000 onwards, several articles were published referring to children's agency from a developmental perspective, mainly from American authors working in various health-related fields such as communicative disorder, nursing, occupational therapy, and nutrition, as well as psychology and philosophy. In most of these articles, agency was explicitly or implicitly defined as being the causal agent in one's own life. For example, in a study examining factors affecting agency in adolescent mothers, DeSocio et al. (2013) defined agency as "the positive expectation of personal control over one's future" (p. 160). Agency was used to refer to the child who exists as a person and gradually develops greater agency related to his or her self.

The specific attributes of children's agency identified from the literature adopting a developmental perspective are: (a) ability to attend to one's self needs, (b) ability to direct future possibilities (e.g. through decision-making), and (c) confidence in ability to organize and perform certain health behaviors. Also, the idea that agency is part of the child's identity was beginning to appear. In these later articles, agency was described as the result of cognitive



processes through which children gradually build their identity. Younger children were described as lacking agency since they cannot retain memories of experience and do not have a sense of self (Baker, 2013). As children develop and gain a greater sense of self, they are presented as acquiring greater agency.

In these studies, as in the studies referring to Orem's self-care theory, agency was considered to be an empirically measurable concept; positivist or postpositivist frameworks were adopted. Different scales were used to measure various factors presented as constituting agency.

### **Children as Health Change Agents**

Beginning in 2005, increasing research has been published in which health educational interventions were provided to children who were described as "health change agents". Most of these studies were conducted with schoolchildren considered vulnerable, many of which were conducted in developing countries, such as Kenya, Tanzania, India, and Ethiopia. This body of literature is highly varied in terms of disciplinary orientations, but public health research was the most prevalent discipline. In these articles, children were presented as having the potential to be health-promoting actors who can act in larger societal structures, and are not only passive recipients of care.

For the attributes of agency, these articles present children's agency as (1) having the capacity to engage with health knowledge and skills, (2) playing an active role in meeting their own health needs, and (3) influencing the choices of others regarding health behaviors – mainly of their family and community. In contrast to the views of agency presented in previous sections, children were referred to as not only having the ability to attend to their own health needs, but to play an active role in meeting those needs, as well as influence the choices of others. In accordance with this latter view, school-aged children were considered as having the capacity to

act as change agents, which led to children being the agents of health-promoting interventions designed by the researchers.

Most of these articles on children as health change agents have been analyzed as adhering to a postpositivist paradigm. However, in contrast to previous views of children's agency, the developmental view was absent in these articles; school-aged children of all ages were included in the studies with no reference to their developmental capacity to act as change agents.

Moreover, a few articles were identified as constructivist, mainly because of their methodological approach. In these articles, the authors presented a slightly different view of children's agency in which an additional attribute was present: the ability to propose solutions to address problems and act on them to promote health. As a result, these authors considered that children's views should be included in the research process by using means such as photovoice or focus groups to help children express their views more freely.

### **Agency in Childhood Studies**

Starting around the year 2010, various authors situated their work in what is presented as the growing field of childhood studies, and was mainly seen in articles from authors in social sciences, with a few articles from medical anthropology and nursing. This literature was almost exclusively from authors based in the UK and Scandinavian countries, and they situated their work in the context of the UNCRC (1989), which stipulates in articles 12 and 13 that children have participatory rights and that their views should be "given due weight". Children were considered in this literature as active social agents involved in shaping their own lives, as well as the lives of others. Agency was presented as not being related to age or other personal/social characteristics, but being present in all children.

The specific attributes of agency that were common in these articles were analyzed as the capacity to: (a) act; (b) shape one's life; (c) have an influence on other human beings; and (d) "actively reflect on and construct their social worlds" (Hampshire et al., p. 702). Olli et al. (2012), in their literature review of agency in children with disabilities, mentioned that agency exists even in cases when the child's self-expression is misunderstood or the child is not allowed to have an influence. From this perspective, agency is not something that develops over time as described in the developmental view, but is seen as being always present in children. Consequently to this view, children were perceived as active agents during clinical encounters, in which they can speak for themselves and be an integral part of the health decisions that are made, as well as processes related to health decisions.

Of all the articles sharing this conception of children's agency, none adhered to a postpositivist paradigm; most drew on a constructivist and/or participatory paradigm. In research adopting a participatory approach, studies were conducted as to involve children in the research, with different levels of children's involvement.

## **Discussion**

The clinical and research implications of adopting a particular view of children's agency are addressed here, aiming to answer the questions outlined in the introduction of the paper. The questions are addressed concurrently in the following discussion, concluding with a tentative definition of agency.

### **Implications of Children's Agency in Research Inquiries**

**Children as objects of research.** The manner in which children's agency is conceptualized has a significant impact on how children will be considered in a scientific inquiry. When looking at Orem's self-care theory, children were initially perceived as having no

agency at all, and research that aimed to study children focused on parents as the dependent care agents fully responsible for the children's health and well-being. Gradually, this view began to shift, as more authors published articles in which children were perceived as gradually acquiring agency. Initially, only adolescents were considered in these studies, since they were perceived as having more agential capacities—defined in terms of autonomy and cognitive abilities—than younger children. James (2009) considers that this view is the result of the dominance of developmental psychology over a century until the 1970s-80s, a field in which “children were studied predominantly as representatives of a category whose significance lay, primarily, in what they revealed about adult life” (p. 35). Children were thus studied, and still are by certain researchers, to discover the universal stages of development that characterize the passage from children—defined as incomplete and dependent *becomings*—to adults who are full beings with individual agency and rational capabilities. In the health-related literature, this view was prevalent from the appearance of the concept of children's agency in the late 1980s, until the arrival of the concept of children as health change agents in the years 2000. In studies adopting a developmental view, children were described as the *object* of research and it was assumed that children's agency could be studied in an objective manner, through the measurement of factors associated with agency. Consistent with the tenets of positivism, the results of these studies were considered applicable to all children, independent of context.

**Children as actors.** In the studies referring to children as health change agents, the authors considered that children could play a role in influencing health care behaviors and bring about change at the personal, familial, and community levels. Children were described as active agents and not only as passive recipients of the care of others. However, in the articles identified for this analysis as adhering to a positivist/postpositivist paradigm, children were assumed to

need adults to guide the change process, and children's views were not included in the identification of issues and solutions. This perspective contrasts with the dominant view in childhood studies related to children as agents. For example, Dedding et al. (2014), in an article reporting on a participatory-action research study conducted with children with diabetes, concluded: "In fact, if we think that children can only participate when they are invited and facilitated by adults or in specially designed projects, we might even be contributing to the reification of the child as passive recipient of care" (p. 8). Consistent with this latter view, using the term *actor* might be more reflective of the role children had in the postpositivist studies of children as health change agents, in the sense that they could do something (i.e. act) and influence others, but were not authentically agential in that they were not actively *reflecting* on their lives and *shaping* their worlds and the worlds of others. Children were mainly included in the research process as actors who, with adequate education, could bring about change.

**Children as agents.** In the articles adopting a constructivist or participatory paradigm, children were significantly more involved in the research process and there was a stated recognition of the role children can play in constructing their social worlds. In a participatory paradigm, there is a political participation described as a right of people to participate in the different steps of the research that aims to generate knowledge about them. This right is deemed a basic human right (Heron and Reason, 1997), which is considered applicable to children in these studies in accordance with the UNCRC (1989). Consistent with this perspective, researchers need to find ways to involve children directly in the research process, and co-create knowledge of relevance to the children themselves. Dedding et al. (2014) used such an approach and involved children as co-researchers who developed and evaluated interventions.

### **Agency: a “Fuzzy” Concept**

While performing the data collection and analysis, multiple types of agency were identified in relation to children, and it was questioned whether all these variations should be included or not. Considering the limited amount of articles addressing children’s agency within the health literature, it was decided to include all the variations, since they were all related to the concept of interest. As presented above, some articles referred to self-care or change agency, while others referred to personal, human, social, or moral agency, as well as agency alone. The inclusion of all these variations is consistent with Rodgers’ view that the same idea can be worded differently, and that exploring these different terms can provide valuable information on the concept of interest (2000).

Also, the concept of autonomy was included in this analysis as it was considered a possible surrogate term for agency. However, after having performed the analysis, it appeared that autonomy would be more a related than a surrogate term for agency, in the sense that it shares some similarities with agency, but not the same attributes. Autonomy was used to refer almost exclusively to the capacity to make an informed decision, often in a legal context related to the child’s capacity to consent. In contrast, agency widely referred to the ability to attend to one’s self needs, in addition to the capacity to make an informed decision.

### **A Tentative Definition of Agency**

An attempt has been made to develop a definition of children’s agency that would reflect the evolution of the concept within the health literature. It was noticed that agency was initially defined in terms of abilities and later of capacities. These terms were not explicitly defined in the articles, but a common distinction between the two is that abilities are learned, while capacities are inborn (Grammarist, 2014). This change in vocabulary might reflect the distinction between

agency as a learned ability in line with the view from developmental psychology, and agency as applying to all children independent of their developmental status, as seen in studies referring to children as health change agents and from the field of childhood studies.

Based on the analysis performed, children's agency could be defined as children's capacity to act deliberately, speak for oneself, and actively reflect on their social worlds, shaping their lives and the lives of others. This definition entails that multiple forms of expression can be used to speak for oneself, including speech and bodily expressions, and that the capacity of children to enact agency is not dependent on adults as facilitators of agency. This definition is only tentative in that concepts are seen as dynamic in nature, changing with time and context (Rodgers, 2000). It is closely linked to the definition of researchers from the field of childhood studies, which is the latest trend in the evolution of the concept, and represents a more social view of agency.

It is hoped that this exploration of the concept of children's agency will help advance the understanding of how the health literature engages with this concept. An exploration of children's agency within different bodies of literature such as in education, law, history, anthropology, and sociology, would be particularly interesting as it could examine paradigmatic differences in how agency is conceptualized, and explore disciplinary similarities and differences. In addition, this broader exploration might allow for a more in-depth comparison of the different variations of agency that were seen in this analysis, particularly the difference between the concepts of social and moral agency in children. An examination of the practical implications of children's agency could also be highly relevant; the ethical consequences of agency in relation to the best interests standard have not been formerly addressed here and would need to be investigated further.