

**PLAYFUL STRATEGIES FOR DATA COLLECTION WITH
CHILD CANCER PATIENTS: AN INTEGRATIVE REVIEW**

Amanda Mota Pacciulio SPOSITO^a, Valéria de Cássia SPARAPANI^b, Luzia Iara PFEIFER^c,
Regina Aparecida Garcia de LIMA^d, Lucila Castanheira NASCIMENTO^e

ABSTRACT

Children are the best sources of information on their experiences and opinions, and qualitative studies have favored the development and application of techniques that facilitate their self-expression and approaching the researcher. Through an integrative literature review, the objective of this research was to identify playful resources used in qualitative research data collection with child cancer patients, and their forms of application. Systemized searches of electronic databases and a virtual library were undertaken, which, combined with a non-systemized sample, totaled 15 studies spanning the period from 2000 and 2010. Drawing, toys, puppets, photography and creativity and sensitivity dynamics were identified which, in association with interviews or not, were shown to directly or indirectly facilitate data collection, thereby broadening the interaction with the children, and permitting further expression of their feelings. The advantages and limitations of using these resources are presented, thus contributing to planning research with children.

Descriptors: Data collection. Qualitative research. Child. Neoplasm.

RESUMO

As crianças são as melhores fontes de informação sobre suas experiências e opiniões; e as pesquisas qualitativas têm privilegiado desenvolver e aplicar técnicas que deem vozes a elas e facilitem a sua aproximação com o pesquisador. Objetivou-se identificar, mediante revisão integrativa da literatura, recursos lúdicos utilizados na coleta de dados de pesquisas qualitativas com crianças com câncer e suas formas de aplicação. Realizaram-se buscas sistematizadas em bases de dados eletrônicas e biblioteca virtual, que, somadas a uma amostra não sistematizada, abrangendo o período de 2000 a 2010, totalizaram 15 estudos. Identificaram-se os recursos de desenho, brinquedo terapêutico, fantoche, fotografia e dinâmicas de criatividade e sensibilidade que, associados ou não à entrevista, mostraram-se facilitadores da coleta de dados, direta ou indiretamente, ampliando a interação com as crianças e permitindo maior expressão de seus sentimentos. São apresentadas vantagens e limitações da utilização desses recursos, contribuindo-se para o planejamento de pesquisas com crianças.

Descritores: Coleta de dados. Pesquisa qualitativa. Criança. Neoplasias.

Título: Estratégias lúdicas de coleta de dados com crianças com câncer: revisão integrativa.

a Occupational therapist, University Hospital, Ribeirão Preto School of Medicine, University of São Paulo. M.Sc. in nursing, University of São Paulo at Ribeirão Preto College of Nursing. Ribeirão Preto, São Paulo, Brazil.

b Pediatric Nurse, Emergency Care Unit, University Hospital, Ribeirão Preto School of Medicine, University of São Paulo Student of the Doctoral Program at University of São Paulo at Ribeirão Preto College of Nursing. Ribeirão Preto, São Paulo, Brazil.

c Occupational therapist. Ph.D., Professor, Department of Neuro and Behavioral Sciences, Ribeirão Preto School of Medicine, University of São Paulo. Ribeirão Preto, São Paulo, Brazil.

d RN. Full Professor, Department of Maternal-Child Nursing and Public Health, University of São Paulo at Ribeirão Preto College of Nursing. Ribeirão Preto, São Paulo, Brazil.

e RN. Associate Professor, Department of Maternal-Child Nursing and Public Health, University of São Paulo at Ribeirão Preto College of Nursing. Ribeirão Preto, São Paulo, Brazil.

RESUMEN

Los niños son las mejores fuentes de información sobre sus experiencias y opiniones e investigaciones cualitativas han privilegiado el desarrollo y la aplicación de técnicas que les den voces y faciliten su aproximación con el investigador. La finalidad fue identificar, mediante revisión integradora de la literatura, recursos lúdicos utilizados para recolectar datos con niños con cáncer y sus formas de aplicación. Fueron efectuadas búsquedas sistematizadas en bases de datos electrónicas y biblioteca virtual que, sumadas a una muestra no sistematizada, del 2000 al 2010, totalizaron 15 estudios. Fueron identificados los recursos de diseño, juguete terapéutico, fantoche, fotografía y dinámicas de creatividad y sensibilidad que, asociados o no a la entrevista, se mostraron facilitadores de la recolección de datos, directa o indirectamente, ampliando la interacción con los niños y permitiendo mayor expresión de sus sentimientos. Se presentan ventajas y limitaciones de estos recursos, contribuyendo a la planificación de investigaciones con niños.

Descriptor: Recolección de datos. Investigación cualitativa. Niño. Neoplasias.

Título: Estrategias lúdicas de recolección de datos con niños con cáncer: revisión integradora.

INTRODUCTION

As a result of the constant advances in the treatment of childhood cancer, today the majority of patients are cured.⁽¹⁾ However, treatment of childhood cancer remains prolonged, requiring considerable hospitalization time, and exposing the child to physically and emotionally invasive and unpleasant procedures.⁽²⁻³⁾

Research that involves child cancer patients should consider the physical, emotional and social repercussions of the illness, and overcome the tendency to consider children as passive and dependent, incapable of understanding research objectives and expressing their own opinions.⁽⁴⁻⁵⁾ Despite children being capable of communicating their feelings, ideas and responses, many find it difficult to express themselves in response to direct questions. For data collection, this requires the researcher to enter into the child's world through the use of creative resources that are familiar to children.^(3,6) Bringing together scientific work that presents different resources used for data collection, and presentation of their advantages and limitations in a systematized manner, can favor the systematization of knowledge about appropriate strategies for research with children. Through an integrative literature review, this research had the objective to identify playful resources used in qualitative research data collection with child cancer patients, and their application forms.

METHODOLOGY

Research methodology included an integrative literature review with the purpose of bringing

together and synthesizing research results on a specific theme or question in a systematic and orderly manner, thus contributing to increase knowledge on this subject.⁽⁷⁾ In order to carry out this review, the five steps⁽⁸⁾ specified below were followed.

To formulate the problem, the guiding question was developed: what are the different playful strategies used, alone or in association with interviews and observation, to facilitate expression and communication by child patients with cancer, in order to obtain qualitative research data? Data collection was performed using key words and descriptors from the Health Sciences Descriptors (DeCS) web site and Medical Subject Headings (MeSH) databases, in different combinations: *criança*/child; *câncer*/cancer; *entrevista*/interview; *fantoche*/puppet; *brincar*/play; *fotografia*/photography; *desenho*/drawing; *pintura*/painting; *brinquedo terapêutico*/therapeutic play; *pesquisa qualitativa*/qualitative research; *coleta de dados*/data collection. These terms were researched in the following databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, ISI Web of Knowledge, Latin American and Caribbean Health Sciences Literature (LILACS), Psychology Information (PsycINFO) and Scopus, as well as in the Scientific Electronic Library Online (SciELO) virtual library.

Inclusion criteria for the literature review included: being a qualitative study; published between January 2000 and December 2010; include child cancer patients as study participants; use of any playful strategy for data collection, alone or in association with interviews and observation; and be written in Portuguese, English, Spanish or French. Articles were excluded if they were published before 2000; were quantitative; entailed research

with child participants with other pathologies, or adolescents and adults; and those that only used interviews, questionnaires or observation for data collection. Articles in other languages were not found. By reading their titles and abstracts, two researchers (first and last authors listed above) worked independently to select the articles. Despite doubts about the adequacy of the studies, the articles were read in their entirety and disagreements between the researchers were discussed, until a consensus was reached. Studies that had a mixed research population (for example, children and adolescents, or children and family members), yet met the other inclusion criteria were also considered, with the goal of not losing relevant data for the review. Yet it is emphasized that extraction and analysis were done taking into account only data relevant to the child population, when this separation by age group was also valued by the authors of the articles,^(5,9) including distinguishing the playful resources used in the interviews. In studies in which this division was not presented in the methodological design of the study,⁽¹⁰⁻¹⁴⁾ it was assumed that the study authors judged that the resources made similar data possible in all age groups evaluated.

Of the 123 studies found, repetitions between the databases and virtual library were excluded, and eight articles met the inclusion criteria of this study. Added to this sample were studies intentionally selected from the personal files of the authors, as well as others obtained through references of the articles included in the systematized search, a strategy indicated by some authors,⁽¹⁵⁾ totaling a sample of 15 studies.

For data extraction, each article was initially classified according to authors, origin country of the study, publication year, authors' professional training and research objective. Next, data was extracted that was specifically related to different playful strategies used to facilitate the expression and communication of child cancer patients during data collection, as well as aspects related to application of the techniques, and their advantages and limitations, as noted by the authors. In the analysis and interpretation of data, the extracted information was compared, and the similar contents were grouped into categories representing the most significant themes of the analysis, which will be detailed and discussed in the presentation of the results.

RESULTS

The 15 studies that composed the review are presented in Table 1. Most of the studies were conducted in Brazil (n=7) and England (n=5), including one partnership with the United States. The exclusively English studies had authors in common, indicating that they were developed by the same group of researchers. Studies developed in Canada (n=2) and Italy (n=1) were also found.

In the ten years analyzed, we found studies published starting in 2002, although most were published in 2008, which had six scientific studies. The majority (n=12) of the studies were authored by nurses; the others were written by psychologists (n=6), physicians (n=4), a recreation specialist (n=1) and an unspecified health professional (n=1).

Based on the terminology used by the researchers themselves, data collection instruments included semi-structured interviews (n=3), unstructured interviews (n=1) and unspecified interviews (n=4); participant observation (n=2) and exploratory observation (n=1); and group discussions (n=1). In regard to playful strategies, the studies registered the use of one or more resources: drawing (n=7); puppets (n=4); photographs (n=4); toys (n=3); collages (n=2) and play dough models (n=1).

Data collection resources

Drawing (n=7)

Research that used drawings for data collection was done alone⁽²¹⁾ or combined with writing,^(5,9,16) graphic and expressive techniques,⁽¹⁴⁾ interviews,⁽¹¹⁻¹²⁾ participant observation⁽¹²⁾ or even with the oral description provided by the child about the illustration produced.^(5,9,11,16)

Three studies^(5,9,16) used the technique called "draw and write," in which pencil and paper were provided to children aged six to twelve years, who were asked to draw a figure relevant to the research theme, and add captions with descriptive texts. The children were then encouraged to discuss their drawings. The data collection location included the children's homes,⁽¹⁶⁾ the hospital,⁽⁹⁾ and an unspecified place.⁽⁵⁾

In another study,⁽¹¹⁾ the participants' ages varied from four to 14 years, and they were interviewed in the outpatient care unit of a pediatric hospital.

Year and authors	Study participants' ages	Study objective (s)	Primary data collection techniques
Gibson et al. (2010) ⁽⁵⁾	4 to 19 years	To explore experiences and opinions of the patients about the cancer treatment, and present a conceptual model of communication and information sharing.	Puppets and "draw and write" technique
Ribeiro et al. (2009) ⁽¹³⁾	6 to 14 years	To understand the experience of the children who are Port-a-Cath carriers, and provide them with a means of alleviation.	Dramatic therapeutic play
Soanes et al. (2009) ⁽⁹⁾	4 to 13 years	To research the experiences of children and adolescents with cerebral tumors, and those of their family members, in order to identify areas of care that can be improved.	Photographs and the "draw and write" technique.
Aldiss et al. (2009) ⁽³⁾	4 to 6 years	To investigate the opinions and perceptions of children and adolescents with cancer about health care services.	Lottery game with photographs and puppets.
Horstman et al. (2008) ⁽¹⁶⁾	6 to 12 years	To investigate children's perceptions about the need for care and support, as well as treatment and health care services.	"Draw and write" technique.
Silva et al. (2008) ⁽¹⁷⁾	School age	Describe and analyze the mediators used in toys and games by the child cancer patient in outpatient care.	Creativity and sensitivity dynamics
Epstein et al. (2008) ⁽⁶⁾	6 to 8 years	To describe the children's opinions about the camping activity, and explore the use of puppets, and justify their validity, for data collection.	Puppets and photographs
Almeida (2005) ⁽¹⁸⁾	3 to 5 years	To understand the feelings experienced by the child cancer patient in regard to his/her illness and hospitalization, and identify the meaning that s/he gives to death when s/he plays.	Therapeutic play
Melro Filha (2008) ⁽¹⁹⁾	5 to 10 years	To understand the meaning that the child gives to the illness and to the hospitalization process.	Puppets
Epstein et al. (2006) ⁽¹⁰⁾	6 to 16 years	To describe the children's opinions about the camping activity and discuss ethical and methodological questions regarding the use of photographs in interviews with children.	Photographs
Massimo e Zarri (2006) ⁽¹¹⁾	4 to 14 years	To investigate the emotional state of the child cancer patient and reduce the stress generated by the hospitalization.	Drawings
Rollins (2005) ⁽¹²⁾	7 to 18 years	To explore and compare the stress factors to which children are exposed in the United States and England; to explore their coping strategies; and examine the validity of the design to facilitate communication.	Drawings
Maria et al. (2003) ⁽²⁰⁾	3 years	To identify the reactions of children to intrathecal chemotherapy, and examine the way in which they use the materials during the dramatic therapeutic play session.	Therapeutic play

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Motta e Enumo (2002) ⁽²¹⁾	6 to 12 years	To identify and evaluate strategies used by children to cope with hospitalization; analyze the importance given to play and develop a proposal to evaluate the hospitalization coping strategies.	Drawings
Wayhs e Souza (2002) ⁽¹⁴⁾	3 to 14 years	To allow the children diagnosed with cancer to express themselves through the images of what it means to be in the hospital.	Playful workshop (drawings, collages, models with play dough)

Table 1 – Articles selected to compose the review. Ribeirão Preto, São Paulo, 2011.

The child was free to determine the theme of each drawing, which was accompanied with an interview and a written description by the child about the illustration. In cases in which this was not possible, the written explanation of the illustration was done by the recreation specialist or psychologist. One study⁽¹²⁾ used participant observation and an unstructured interview with children and adolescents aged from seven to 18 years, in addition to three drawing techniques: “Drawing of a Person Picking an Apple from a Tree;” “Scariest Image Drawing;” and “Closure Drawing”. Based on the self-report of the child, the first technique sought to obtain psychological measures. The last two techniques permitted the expression of the participants’ greatest fears and the closing of the session in a pleasurable manner. All interviews and application of the techniques were done in the hospital ward, hospital park, or in the waiting room of a laboratory outside of the hospital.

A differentiated approach was identified in the study⁽²¹⁾ in which a test was performed with children aged six to twelve years, to validate the Coping Hospitalization Assessment Instrument, which included boards with drawings that represented possible coping strategies and, more specifically, the importance attributed to play as one of these strategies. Based on the drawings presented, the children were asked to identify attitudes and activities that they “always,” “almost always,” “sometimes,” or “never” do, with the objective of facilitating their ability to cope with the hospitalization.

Only one study⁽¹⁴⁾ performed a playful workshop, in which children and adolescents aged from three to 14 were invited to use drawings, collages, models or another graphic technique of their choice to express their hospitalization experience. A single

workshop was carried out, which lasted about one hour and thirty minutes.

Toys - Therapeutic play (n=3)

Three studies^(13,18,20) opted for this research data collection technique. Dolls representing members of the family and health care team were used, along with home and hospital-use objects. Drawing and painting⁽¹³⁾ materials were made available, along with a doll that permitted visualization of the organs of the body.⁽²⁰⁾

Children aged three to nine years, and one adolescent aged 14, participated in these studies. The individual dramatic play sessions were done in an outpatient context,⁽¹³⁾ and with children hospitalized in an oncological unit.⁽¹⁸⁾

In another study,⁽²⁰⁾ the children were invited specifically to play in the outpatient unit “like a child who received medication in his/her back,” one week after having received intrathecal chemotherapy. The sessions varied from 45 to 60 minutes.

Puppets (n=4)

Of the studies reviewed, four used puppets to interview the children.^(3,5-6,19) The studies had the objective to investigate the experiences, perceptions and opinions about the illness and treatment.

The puppets were used with children aged from four to eight years. The locations chosen to perform the interview with puppets were the hospital nursing ward and outpatient care unit,^(3,5-6,19) and children’s homes.^(3,6) Further, two studies collected data in both the children’s homes^(3,6) and the hospital, specifically a recreation room⁽¹⁹⁾ and a

private room, both unknown to the child until the time of the interview.⁽⁶⁾

Three studies^(3,6,19) reported some type of strategy to build closeness with the children before the interview. One of these⁽³⁾ reported using a game with photographs of facial expressions, which were later used during the interview with the puppet; the other studies described prior handling⁽⁶⁾ or creation of the puppet by the child.⁽¹⁹⁾ In the majority of studies,^(3,5-6) the puppet was created with prefabricated stuffed animals. For data collection, two studies^(3,5) reported the participation of a researcher specialized in games/toys, and another⁽⁶⁾ stated that the interviewer was a pediatric nurse with previous experience using puppets. Some studies discussed the encouragement given to the child for her to dramatize⁽¹⁹⁾ and create characters, and converse with the other puppet, if this was his/her desire.⁽⁶⁾ Just one study⁽⁶⁾ reported that the application time of the technique varied from 30 to 120 minutes.

Photographs (n=4)

With participants aged four to 16, photography was used as a resource to complement the semi structured interview, with or without the use of puppets, or as the primary data collection technique.

One of these studies⁽⁹⁾ used the modified “Mosaic Approach” technique, in which the child has a camera during one week to record any aspect of his/her experience, diagnosis or treatment that s/he considers important. After one week, the child met with a recreation specialist, with whom s/he developed a poster of his/her photos with added text and drawings, while the child recounted his/her stories and motives. The environment in which the data collection took place was not reported.

In another study,⁽³⁾ photographs taken of children with different facial expressions were used in a game, before the interview began, as a strategy to build closeness between the researcher closer to the child. The same photographs were used with three children during the interview, to help them to express different emotions.

The evaluation of a camping activity for child cancer patients through the presentation of photographs was treated in two studies^(6,10) which complemented each other, yet only one of which⁽¹⁰⁾ described and detailed the technique. Semi structured interviews were performed in the hospital or

children’s homes, one week after the participants returned from the camping. Thirteen color photos were used that were taken by the researchers, and recorded physical structures, and the natural and social environment of the camping.

Dynamics of creativity and sensitivity (n=1)

One study⁽¹⁷⁾ created the dynamic of creativity and sensitivity for data collection according to the creative and sensitive method, during which a group discussion about artwork and participant observation were simultaneously carried out. The “scene play” dynamic was performed in outpatient care with twelve school age children using colored pens, colored pencils, crayons, wrapping paper, *papier-maché*, miniature toys and play dough.

DISCUSSION

Children can provide necessary information about their experiences, yet to actively involve them in research, it is necessary to use techniques and resources other than those used in studies with adult participants.⁽²²⁾ Researchers need to be conscious of the advantages and disadvantages of the use of each strategy, as well as of the implications for the data produced in the research.⁽¹⁶⁾

It is notable that the data collection resources presented in this review are not techniques that are disseminated in various countries, which emphasized the need to publicize these strategies as a method to stimulate and provide for their use in new research.

Among the ethical considerations pointed out in the studies is the concern to respect the children’s freedom to use (or not) the playful resources. Thus, researchers should be prepared for situations in which the children choose not to use the materials, which can cause feelings of frustration. To obtain the children’s consent is an amply used practice, yet it is important to emphasize that this is not a legal procedure that guarantees the children’s freedom to express their desire (or not) to participate in the research, and demonstrates the care of the researchers in relation to these.⁽²³⁾

Overall, the studies describe the technique used in detail, making clear the questions directed to the child or even the method of asking them, which can facilitate the use of these resources in

future research. However, the authors emphasize the importance that these strategies are applied by trained researchers, who are familiar with the use of playful resources.

The application time of the techniques varied from 30 to 120 minutes, indicating their attractiveness and great interest that the children demonstrated in these playful methods, because they remained engaged in the activity despite their illness and possible discomfort resulting from their health conditions.

Advantages of the use of diversified strategies for data collection

For most children, drawing is an entertaining activity, and can be used to facilitate communication between them and the researchers, and to build the participants' trust and motivation.⁽¹⁶⁾ Children may find it difficult to verbally communicate their feelings, fears and opinions, and the drawings facilitate this expression.⁽²⁴⁾ One of the studies⁽¹²⁾ also discussed the use of the drawings as an interview trigger: after feeling more comfortable and safe, the child can communicate feelings that s/he did not represent in his/her illustration, but would like to share with the researcher.

The playful nature of the proposition of boards with ready designs in the Coping Hospitalization Assessment Instrument was shown to be capable of engaging and encouraging participation of the child cancer patient in the interview, and amplifying his/her possibilities to express his/her feelings, behaviors and thoughts. This can be proven in light of the difference of content obtained through the open questions and those questions intermediated by the boards, both parts of the same instrument.⁽²¹⁾

In regard to the use of toys in therapeutic play, this was shown to be an excellent resource in order to know the reactions and feelings manifested by the children, in addition to encouraging a closer relationship between the children and researchers, which took the data collected to a deeper level.⁽²⁰⁾

The studies^(3,5) that used puppets as a resource for data collection cited the need for greater closeness between the researcher and child. The puppet permitted the authors to enter into the world familiar to the child, that of drawings, animals, stuffed animals and stories. Additionally, the puppet was

used to stimulate the response to the researchers questions,^(6,19) and did not require the participant to speak directly with the interviewer or maintain eye contact, which is difficult for some children.⁽³⁾

The increased verbal expression of the children, and greater closeness in the researcher-participant relationship, through the use of puppets in studies with child cancer patients has also been attained in other studies, confirming the success of this strategy.⁽²⁵⁻²⁶⁾ The studies used the puppets with children between the ages of four and eight, yet there are studies in which the age range of the participants extends to twelve years.^(25,27)

The Mosaic Approach was shown to be an interactive process of data collection that is useful to reveal the social context of the child cancer patient, as well as his/her vision of the world and events.⁽⁹⁾ The use of photographs was also considered to facilitate the researcher-participant relationship, in addition to creating an informal atmosphere during the interview, capable of moving the focus away from questions and responses, which generally fall on the child.⁽¹⁰⁾

The dynamics of creativity and sensitivity were also shown to be effective strategies for communication with child cancer patients, making it possible for participants to express what they thought and said about themselves, their values and beliefs by taking artistic production as the reference point.⁽¹⁷⁾

All of the play techniques used had the advantage of being possible to be applied in the hospital (outpatient or infirmary) and at home, making them important tools to access the subjectivity of the participants, and facilitating the children's closeness and interaction with the researcher.

Limitations to the use of differentiated strategies for data collection

In some situations, as pointed out by the researchers from one of the studies,⁽⁹⁾ the use of images such as drawings or photographs is more useful to provide for integration and closeness between the researcher and participants, being the basis for the interview or discussion that follows, rather than the source of data itself.

Some studies^(11,16) indicated that the use of drawings as a resource for data collection has disadvantages related to difficulty of analysis and

interpretation of the illustrations. In regard to the use of photographs, one study⁽¹⁰⁾ only used pictures brought by the researchers, and pointed out that the collection and analysis of the data would have been enriched if personal photographs had been included, spontaneously shared by the participants.

One play technique was used in several different studies⁽¹⁰⁻¹⁴⁾ as a resource to assist the interview and observation in an undifferentiated manner with children and adolescents, making its applicability by other researchers difficult, since these studies did not detail which age group was more attracted to the playful resource, or even if there was more resistance or difficulty with one specific age group. Children have needs and characteristics that are particular to their current development stage,⁽²⁸⁾ in this way, research with child participants should pay attention to these singularities, and use methods that are appropriate and attractive to each age group.

CONCLUSION

It is always challenging to find methods of data collection that enthruse child cancer patients and are suitable to their clinical conditions. Yet this review identified in the literature playful resources that were successfully used in qualitative research with child cancer patients, and showed their forms of application. The resources discussed in this review were shown to facilitate data collection, directly or indirectly; they made it possible for the children to express their feelings, fears, opinions and doubts, and corresponded to an ethical need to adapt the techniques to the age range and social context of the participants, in addition to respecting their autonomy. In spite of the advantages of the use of these resources, this review points to the need and possibility to develop new research in order to strengthen their applicability.

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**Author's address / Endereço do autor /
Dirección del autor**

Lucila Castanheira Nascimento
Escola de Enfermagem de Ribeirão Preto, USP
Av. Bandeirantes, 3900, Monte Alegre
14040-902, Ribeirão Preto, SP
E-mail: lucila@eerp.usp.br

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