The therapeutic itinerary in urgent/emergency pediatric situations in a maroon community

Abstract The goal was to understand the therapeutic itinerary of Maroon children in urgent/emergency situation. Is a descriptive research with a qualitative approach that uses the Health Care System model of Arthur Kleinman as its theoretical support. Participants included 12 mothers of children who had experienced any urgent or emergency medical situation. Data collection took place from December 2013 to June 2014 through semi-structured interviews with a thematic analysis of the data. The care of the child started in the “informal” subsystem, and access to a “formal” subsystem was characterized as a pilgrimage for health services. A development of specific strategies is needed to ensure and facilitate full access to the services of the professional subsystem for Maroon communities.

Key words Child care, Emergency Medical Services, Demand for health services
Introduction

The term “therapeutic itinerary” (TI) refers to the search for treatment and seeks to describe and analyze individual and socio-cultural practices, in terms of the paths taken by individuals to solve their health problems, including the logic that drives this pursuit, which is woven in multiple formal and informal networks of support to which a person belongs.

The early work on TI originated from the term illness behavior - translated as sick behavior - which was assumed to be the conduct of individuals searching for care and was rationally oriented, considering the question of cost-effectiveness. This behavior was considered voluntary, rationalistic and individualistic. Later, this concept was expanded to include cultural values in the responses of individuals. Thus, culture can be considered a determining factor of TI, as culture influences how people communicate, perpetuate and develop knowledge and activities in relation to life, including the realm of health care.

Since the 1980s, the influence of culture on the perceptions of health, disease and health care has been addressed by anthropologists such as Arthur Kleinman, who recognized the existence of a cultural system, i.e., the Health for Care System, which includes three interrelated subsystems: the popular subsystem, the folk subsystem (informal system) and the professional subsystem (formal system). The explanatory models for these subsystems are based on concepts that lead to the perception and interpretation of disease and allow for developing different curing mechanisms consistent with the cultural context of each individual and group.

In addition to reflecting the cultural factors, the transit of individuals by social devices in search of care demonstrates the influence of socioeconomics on healthcare, as TI practices reveal strategies for populations to cope with their health problems, especially the poor, who stand out among Maroon populations.

Maroons, defined (in Brazil) as ethno-racial groups of black ancestry and distributed throughout this country, have consolidated territories in peripheral regions and are therefore subject to the consequences of geographic isolation, one factor that causes uncertain access to health care services, especially more complex health care such as urgent or emergency services.

Situations characterized as urgent/emergency conditions are unforeseen health problems in need of immediate medical attention because of the potential risk to life, be it imminent or not.

Although they affect people of all age groups, urgencies/emergencies in children have a significant importance due to both psychological and biological idiosyncrasies, as well as the physical and cognitive abilities, dependency levels, activities and risk behaviors of the children; in addition, mechanisms to cope with health problems have not been developed in children, and this fact characterizes these individuals as vulnerable beings.

Urgent/emergency situations in childhood, especially those related to external causes, persists as a major public health problem that requires urgent attention and is the leading cause of death among children worldwide; this is especially true in low- and middle-income groups, which account for more than 95% of cases, because children living in poverty and in rural and remote areas are more vulnerable, as is usually the case with children in maroon communities.

Given this context, questions arise regarding how people in Maroon communities proffer care to children in urgent/emergency situations in the healthcare system; here, this topic is analyzed from the aspect of TIs.

There are recent studies regarding TIs in Brazil; however, they do not focus on maroon communities. Conducting research to reveal the care practices and difficulties faced in the search for health services in these communities is important in order to support the development and implementation of public policies that enable full access to healthcare for these individuals.

Given the abovementioned facts, this study aims to evaluate the TI adopted by Maroons in emergencies and pediatric emergencies and to demonstrate the care practices of the informal subsystem, including the journeys made in the formal system, focusing on user access.

Methods

This is a descriptive research study with a qualitative approach that uses the healthcare system model of Arthur Kleinman as is theoretical support. The locus of the study was the maroon community of Praia Grande, located on Maré Island in Salvador (BA). This community was chosen because of its lack of emergency services and because it is a population with a broad cultural heritage, which is related to an African heritage.

The eligibility criteria for participants were inhabitant of Praia Grande aged over 18 years at the time of conducting the survey; father, mother
or guardian of a child age 0 to 11 years, 11 mon-
ths and 29 days (the Statute of Children and Ado-
lescents\textsuperscript{12} considers one a child up to the age of
twelve years) who has received any type of care in
an emergency situation; voluntary participation
in the study; and without any verbal or cognitive
disabilities.

The number of participants was not defined
prior to the study. Thus, the interviews were held
until a repetition in the responses, with the cor-
responding theoretical saturation of data, was
observed\textsuperscript{13}.

To identify children in the community who
had experienced any urgent/emergency medical
situation, we utilized a partnership with commu-
nity health workers (CHW), representatives of
NGOs and the support of the people themselves
who, through a snowball effect, were referred by
others who met the inclusion criteria of the stu-
dy\textsuperscript{14}. We used a classification system of a health
service of São Paulo\textsuperscript{15} to classify the urgency/
emergency pediatric, which was elected to be the
only system specifically directed to the age group
studied.

Data were collected from December 2013 to
June 2014 after approval by the Ethics Committee
of the Federal University of Bahia, and the study
respected the ethical principles established by Re-
solution 466/12 of the Ministry of Health\textsuperscript{16}.

The data collection techniques were 1) an
application form based on the VIGITEL ques-
tionnaire, proposed by the Ministry of Health,
which assessed the socio-demographic characte-
ristics of participants and children to whom as-
sistance was given; 2) a semi-structured interview,
which was to implement a guide that consisted of
semi-open questions allowing for each child’s TI
to be traced by focusing on the care provided to
these children and their paths involving the social
apparatus.

The interviews were individually conducted
in a place chosen by the participants. The inter-
views were recorded and lasted an average of ten
minutes. Later, the interviews were transcribed
and coded with the letter E, followed by a number
in the order in which they were carried out: E1
to E12.

For data analysis the thematic analysis\textsuperscript{17} was
used. The phrase was defined as a registration
unit (UR), and 105 units of thematic analysis
emerged, which were grouped into 26 themes that
will be discussed in two categories: the popular
subsystem, which was the gateway to the care, and
the formal subsystem, which was the pilgrimage
in search of care.

Results and discussion

First, the socio-demographic characteristics of
the participants (Table 1) and the children (Table
2) will be discussed. Subsequently, from the cate-
gories that emerged from the analysis, the inter-
viewees’ perspective will be given, demonstrating
the adopted TIs in urgent/emergency child care.

All the participants were women, mostly bla-
k, and were mothers of the children for whom
care was provided in a situation characterized as
urgent/emergency. At the time of data collection,
the majority of the women were aged 30-39 ye-
ars, married or in a stable relationship, had only
one child and declared themselves to be of an
evangelical religion (Table 1).

Regarding education, the women had either
completed or were attending elementary school.
Regarding occupations, the women predomi-
nantly worked in the shellfish and other profes-
sional activities that did not require qualification
in higher education were also cited, including
artisan, housewife, merchant, child development
aid (ADI) and cleaner (Table 1).

For income, almost all participants were be-
neficiaries of the Family Grant Program, with a
median family income of R $ 890.00 and a hou-
sehold per capita of R $ 212.50, which classifies
these participants as a vulnerable group at a
socioeconomic low level, according to the mu-
unicipal income human development (MIHD)
index\textsuperscript{18,19} (Table 1).

In terms of the children’s characteristics, the
majority (N = 7) of the children were boys, and
the predominant age group (N = 7) was 1-4 years,
followed by children 5-8 years (N = 3) and chil-
dren younger than 1 year (N = 2) at the time they
received urgent/emergency assistance (Table 2).

In terms of their health characteristics, the
majority (N = 10) of children had no underlying
disease; asthma was found in two children, and
in both cases, the asthma caused the emergency
situations. Almost all (N = 10) children did not
have health insurance, and most (N = 8) of the
children used to public service when professional
care was needed. More than half the cases (N =
7) revealed that the child had undergone routine
medical care during the previous year (Table 2).

With respect to the children’s presenting pro-
lems, five diseases were noted, and most of the
diseases were clinical in nature: febrile seizures
(N = 5), fever (N = 3), asthma exacerbation (n =
2), dehydration related to diarrhea and emesis (N
= 1) and burn (N = 1), especially with secondary
convulsions and fever.
The care provided in the popular subsystem is informal in nature, and the medical knowledge is derived from common sense, including the family’s understanding of the illness and the care, as well as the influence of the individual’s social network and community.

In the TIs of this study, the community was the starting point for care provided in this subsystem, and the TI began with the assistance provided by the family, as care is primarily a family matter; it is the family that struggles with the activities of daily living and that handles the pain and existence of serious health problems, as observed in this study, and this circumstance is corroborated by other authors.

Kleinman and Geest recognized the existence of a strong gender bias in the act of caring, so that the family network of care is dominated by women. In agreement with this bias, the all-male composition of the study participants is noted. Males were also invited to participate in the survey; however, they refused and called their wives or other women to do so on the grounds that the women were better able to provide the interview, as they were more knowledgeable about the facts and care provided to the child.

This phenomenon is related to the historical and cultural context of women, in which the female figure is responsible for taking care of her own, and this function or responsibility is considered by all to be innate and natural. In this way, the woman becomes the protagonist in the provision of health care and is responsible for assisting the family; she is the primary, and sometimes the only, caregiver and manager of care in the family, as is shown in related studies.

In terms of care practices, resources corresponding to the explanatory model of the popular subsystem were noted, especially with the use of herbs and fruits to prepare home remedies, baths and showers, as seen in the following statements:

I just gave a home remedy. I gave a piece of paper. It is the pineapple, the pineapple syrup that my mother also makes; the ichneumon banana syrup she makes, and it is syrup...the sheet is...lemon grass, black maria, and quioiô. That is what you can do to fight. (E8)

The neighbors came, and she was given a leaf bath [quioiô] and the remedy [dipirone] until she came back to us. (E6)
The terms neighbors helped and the people taught me reveal, as in the study of Budó et al.\(^2^3\), strengthening of family care by a social support network comprising relatives, friends and neighbors. This phenomenon is a hallmark of the informal subsystem, described by Kleinman as the “popular subsystem” composed of individuals, families and the social arena in which decisions are made about the disease, care and treatment guidance\(^6\). This network is considered by Gutierrez and Minayo\(^2^2\) as a valuable resource and the main source of support, especially among poor families.

In addition to the natural resources used in the familiar and popular subsystem\(^2^9\), self-medication and practices concerning the professional subsystem, such as the use of prescribed medications, were also described. Therefore, there was reconciliation between the resources of the formal and informal care systems, as evidenced in the study by Maliska and Padiilha\(^9\). The medications used included bronchodilators, antibiotics, painkillers and anti-inflammatory agents, especially the informal care system, and this is similar to the results of a study by Souza\(^3^1\):

\[\text{I used a puffer that the doctor himself taught me how to use. In addition to this device that I use when she has this issue, I make her tea ... (E3)}\]

For medicine, I gave her dipyranone and homemade teas. Holy grass tea, lemon balm, fennel, which could be the right vapors? (E5)

As in other studies\(^2^9, 2^9, 3^1\), there is evidence of a cultural influence related to the use of tea and manufactured non-prescription drugs\(^2^3, 2^5, 2^9, 3^1\); this is especially true for dipyranone, which is also highlighted by Pereira et al.\(^3^2\) as a drug of choice for controlling fever because it is freely traded in Latin America, Europe, Africa and Asia and is thus easily available to most of the population\(^3^2\). Self-medication might even stem from the difficulty of obtaining assistance in the professional subsystem\(^3^3\).

In addition to using natural remedies and manufactured drugs, this study also highlighted the use of physical steps to decrease a child’s temperature, for example, bathing with alcohol or immersion in cold water:

\[\text{The other day, he had a seizure at night. Because I have had experience with a girl who was given a bath with alcohol, the alcohol was already purchased and left at home. [...] Then, I did the same thing. (E1)}\]

We put the child in cold water. We actually put the child inside the barrel ... after adding cold water and placing a damp cloth in the barrel. (E2)

Such treatments are considered\(^4^4\) ineffective because they do not alter the hypothalamic set point and hence do not act in the pathophysiological mechanism of fever. However, as explained Arcanjo et al.\(^3^5\), behavior in sickness relates to cultural values, and the choice of treatment demonstrates the expression of the population and is characterized by the use of physical means, defined by Gutierrez and Minayo\(^2^2\) as a culturally crystallized element. As a popular practice inhe-
rent to the subsystem, these methods are used both in maroon communities and by other individuals.

In such care strategies, “massage” is used and is also referred to by Neves and Nunes35 as adjunctive therapy in the informal subsystem of health care:

[... ] My mother took her (the child) and began beating her ... she began to massage her (the child’s) chest ... Then, the house began to fill, the massage continued, and then she started to return to normal ... (E7)

Religiosity appears as a background, so that mothers look to God upon the occurrence of disease in their children, seeking divine guidance about how they should proceed for the resolution of the problem, as seen in this interview:

And I pray; I am still praying and asking for guidance from God, a light ... (E1)

According to Arcanjo et al., recent surveys show the link between health, beliefs and spiritual practices, including prayer, the search for religious services and faith in God. In this sense, seeking the religious sphere is a common strategy in the informal subsystem and is not particular to mothers in this study because this strategy has been identified by other authors23,25,29,33.

In addition to being the place of delivery of care, the family is where a sick person is initially managed and valued29. As highlighted by Kleinman5, it is in this area that decisions are made about when to seek other subsystems.

As Rati et al.36 observed, we also noted that the mothers in this study were limited in caring for their children, and the search for institutionalized care in the formal system occurred, especially when the responses to informal subsystem resources were not positive. This phenomenon has been found in other studies25,29,31:

[... ] I took care of her at home; when it persisted and did not yield any result or with medication, then I took [...]. (E5)

In this study, two of the participants revealed that care was provided only in the informal subsystem. Three participants appealed to the formal subsystem while paying appropriate attention to the informal subsystem. In one case (burn), the child directly entered the formal subsystem, and the remaining six participants completed the TI in the formal subsystem, after an inadequate response from the informal subsystem.

**Formal subsystem: pilgrimage in search for care**

The professional subsystem consists of scientific medicine5, is characterized by organized healing professions and formal learning, is legally recognized and is represented in Western societies as biomedical knowledge37.

According to Rati et al.36, the institution of this subsystem depends on factors such as resolution, quality, specificity in pediatrics, accessibility, geographical location, positive experiences in the past and paid host. However, Marques et al.28 noted that in the poorest strata, such as this community case study, primary care services are frequently used as a regular source of health care.

Similar to the study28 conducted in a quilombo of Minas Gerais, it was observed that the institution representing the nearest formal system of the Maroon community consisted of basic health care services, and this institution was the main source of heat care for children in the event of injuries, including urgent/emergency cases.

It should be noted that the Family Health Unit (FHU) had not yet been established in the maroon community of this study, and the TIs of six participants, for whom the most frequent search for health institutions was in another location, is evidenced in the following interviews:

At that time, one had not been seen yet. [...] We took him to Salvador. (E11)

“However, even after the establishment of USF quilombo, this study showed that in constructing TIs for their children in urgent/emergency situations, mothers looked for help in another location”:

I was not at the local clinic, no. I went to Salvador instead. I prefer to take savior. You arrive at the station ... it is not every day that one finds a doctor, right? (E4)

This statement reflects the mother’s preference to move her child to another location, showing that the population considered care provided in the community as poor, especially with regard to assistance in emergencies and pediatric emergencies. Furthermore, the operation of the local clinic have hours that are limited to the daytime. Thus, this service is unable to meet the needs of night-time injuries, and people need to resort to the mainland for professional care, as voiced by one of the participants:

(Did you take your child to the post?) No, because it was early, and the post was closed here. (E7)

Some mothers (N = 3) showed that the onset of this subsystem in a TI was due to primary
care from the USF. In one case, the participant said the station provided useful assistance. In two other cases, the interviewees reported that they received no assistance from the USF and were told to go to the mainland:

_"I went to the post but, at the same time, they sent her to Salvador." (E3)_

Primary care assistance in cases of urgency and emergency is legally established^38; therefore, this level of care is characterized as a gateway to the Unified Health System (SUS) and as a component of the health care network of the State of Emergency and Emergency Systems that should offer the first service to patients with acute and/or adequate transportation to a hierarchical health service.

As noted in the study of a maroon community by Marques et al.,^28 when mothers are instructed to report to another service, it is considered to be a socioeconomic difficulty, and the vulnerability of this population to obtain primary care are large, depicting the perverse wickedness that the Maroons are submitted to.

This experience breaks the link that should be established between the health care user and this level of health care provided. The bond breakage causes the population to discredit the service, as highlighted by the research of Lago et al.,^39 who describe the TI of users seeking assistance in an emergency department (ED) and the reasons behind this occurrence. The authors showed that 82.6% of participants did not address the core network because they have experienced situations in which they did not receive care for their own medical problem(s) at this level of care. A similar opinion was voiced by one of the mothers in this study, who discredited the health center and considered it as a place only for the realization of “basic advice”:

_What is there must come down. There is nothing. It is a place just for basic queries. It is to obtain a referral, because no relief is ever given. If you come to the station, you die here. I do not take the same position. If it is a serious case, I do not go there. I’ll be straightforward with my opinion, because when arriving there, they send you away, send go outside anyway." (E2)_

In this perspective, the place chosen for treatment reflects the urgency/emergency and is the first patient option due to the lack of confidence in the primary care system, as noted in other studies.^36,39 It should be noted that access of this population to urgent and emergency services requires users to travel great distances because these services are located far from the community.

In pursuit of an ED, study participants revealed that they had to provide for their own means transport to the mainland because there was no connection between primary and emergency care for these cases:

_You must go by boat here, you have to take a boat." (E8)_

Some reports highlighted the difficulties encountered in the transport of sick children:

_On Wednesday, it was back again, the fever, the moaning. So I said ‘I will not wait for a seizure’. My brother was taking me to Botelho. I was walking, braving the mud and all, to take the boat to the hospital." (E1)_

This statement confirms the proposition made by Guerin et al. that to access health services and resolve health problems, the user takes many paths and creates the most appropriate TI. However, as analyzed in this report, in the most appropriate TI, these people are often exposed to inhuman conditions in order to access the institutions of the formal subsystem and ensure the necessary care.

It must be noted that shuttle islanders have fewer difficulties because in some communities that are isolated by a river or the sea, such as the community in this study, rescue transport consists of ambulanchas, which are aquatic vehicles for the provision pre-hospital care. A person can request a ride by number 192 of the Emergency Mobile Emergency Service (EMES), and this can be done either by the maroons or by the health center professionals. In this study, we noted that neither triggered the ambulancha; therefore, in all cases, the participants used the private boats of community residents:

_"[…] I paid to go. For the boat and car." (E6)_

The interview above shows that the mother paid for both the crossing and the inland transport to the US when they reached the continent; at no time in the itinerary was EMES requested. Multiple reasons were cited for not requesting an ambulancha, especially the lack of response to the calls:

_Because I remembered not seeing [an ambulancha]? What I found at the time…I had a boat available, I thought it best to opt for it. Because it is a protocol [to call the ambulance], ok?" (E12)_

_If you expect the ambulance here, you die." (E2)_

These statements demonstrate the difficulty experienced in the TIs of these people regarding access to emergency transport. This is not restricted to the maroon community of this study was and has also been cited by other authors.

Arriving on the continent was not necessarily synonymous with a resolution; thus, in some ca-
ses, the suffering experienced by these mothers did not cease, and the search for care became a pilgrimage within the formal subsystem:

[...] spent time in State General Hospital SGH thinking I was being attended to, but I was not. Then, I was talking and she [bus passenger] saw him moaning. Then, she did so [...] Look, past the Itapuã post (UPA), there is a station that meets and serves people well and gives all tests. I say, is it? I'm already here, I'm going to jump. I thanked her and went down. I went there, to the pro Itapuã post. I arrived at night. That's when he was hospitalized. (E1)

The pilgrimage to seek care is characterized by Deslandes as one of the user forms of exposure to institutional violence. In this sense, we glimpse that this violence is not only witnessed in the arduous journeys undertaken by members of the maroon community to access the formal subsystem but also seen in the treatment given by the professionals of this subsystem, as translated in the following statement:

[...] When one will suit us all ... is very aggressive with us, does not have the patience to refer us to the right person, calmly, sometimes not even giving a shit, right? (E11)

In this report, professionals have a clear disregard for caring for people with low socioeconomic status, which characterizes health inequity. With similar results, Sisson et al. demonstrated in their study that, among other things, dissatisfaction was related to the quality of care provided by professionals such as receptionists and was also related to the lack of individual and special attention given to the patient.

A service is considered good that responds to user demands, which is a determinant of satisfaction with the service. To frequently achieve satisfaction, users have to turn to other institutions, as seen in the following statement:

Then, the doctor also treated me very well, you know what is very well? He did take it; he took the X-ray. That's when he saw that he had a respiratory infection. (E1)

Given the abovementioned details, we note that to achieve the desired care in this subsystem, mothers had to go through multiple paths, which were characterized as a pilgrimage for health services, occurred early on the island and were only completed after attempts to seek care on the continent.

As Ceccim et al. noted, the creation of the SUS represented the extension of “public access to the actions and health services needed by individuals.” We agree, in part, with this statement because the difficulties imposed by access are increased, either by the level of care of these services or by the conduct of the professionals of this subsystem, which sometimes make the paths to achieve care tortuous and therefore cruel.

As Guerin et al. noted, we believe that the pilgrimage mothers who seek to resolve the health issues of their children bring implications of the health system in their itineraries into focus, demonstrating the resoluteness and what “escapes” these services and thus highlighting aspects requiring change to achieve comprehensive care and the resolution of health problems.

Our findings reaffirm that the black population, especially the maroon community, is vulnerable. The question of access to and use of health services was reported by Silva et al. The analysis of TIs for urgency/emergency situations in this community highlights the experiences and trajectories of these people, which may lead to the formation and development of individual projects within this field, and is characterized as a study with the potential to spur governmental action, thus contributing to overcoming the demographic and epidemiological invisibility of this population.

Conclusion

This study showed that in urgency/emergency situations of children in a maroon community, the construction of the therapeutic itinerary takes place both in the informal formal subsystems of health care.

Care began in the popular subsystem with the family and social support network. As a feature of this subsystem, resources of daily life were exploited, with evidence for the use of teas, home remedies, massage and self-medication, all demonstrating the strong cultural mark of this community.

The search for help within the professional subsystem occurred after careful attempts to resolve the health problem in the popular subsystem. This act was seen as a true pilgrimage to health institutions and was characterized by the difficulty of access of the maroon community to the formal health care system. The pilgrimage began in the community with the search for basic services, which proved ineffective in providing assistance in these cases. The pilgrimage continued to other locations, where access to health services was revealed as difficult, and the inequities in health care experienced by the maroon community...
when they require professional assistance were highlighted.

Determining the therapeutic itinerary of this population reveals more than the trajectory of seeking care, because mothers were allowed to share their experiences and express the difficulties faced when they required access to health services. This process unveiled the lack of resolution and welcoming in the professional subsystem, either on their own island or on the mainland.

These results indicate that the maroon population does not have the benefit of full health care and could serve as a basis for formulating public policies to guarantee such access. This access includes the effective implementation of primary care as a gateway and the proper functioning of ambulances to ensure resolution and completeness of SUS.

Collaborations

SMC Siqueira, VS Jesus and CL Camargo participated in all stages of the construction of this article.
References


