

The right to health: challenges revealed by the home care provision in supplementary health services¹

O direito à saúde: desafios revelados na atenção domiciliar na saúde suplementar

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Resumo

O objetivo do estudo foi analisar programas de atenção domiciliar na saúde suplementar do ponto de vista do direito à saúde, a partir de estudo de casos, de natureza qualitativa, desenvolvido em quatro operadoras de saúde no município de Belo Horizonte, Minas Gerais. Os dados empíricos foram obtidos de entrevistas com gestores de operadoras e prestadoras que ofertam programas de atenção domiciliar. Os resultados são discutidos a partir de três eixos analíticos: a oferta da atenção domiciliar e os desafios da universalização do direito à saúde; a relação da saúde suplementar com o sistema público de saúde e com as famílias; e a judicialização como caminho para se garantir o direito à saúde no campo da atenção domiciliar na saúde suplementar. A desregulamentação da atenção domiciliar na saúde suplementar foi revelada como um desafio para a garantia do direito à saúde, prevalecendo a oferta segundo os interesses das operadoras que adotam estratégias para evitar a judicialização, como, por exemplo, não divulgar o benefício. A suspensão da assistência por decisão unilateral da operadora e a transferência de responsabilidades para o sistema público de saúde e para as famílias afrontam o direito dos usuários de receber serviços na modalidade que melhor responda a determinadas situações de saúde. Conclui-se que a atenção domiciliar na saúde suplementar é permeada por tensões que evidenciam a urgência de maior regulamentação no campo. **Palavras-chave:** Cuidados domiciliares de saúde; Regulamentação governamental; Planos de pré-pagamento em saúde.

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Abstract

This study analyzes home care in supplementary health programs from the right-to-health perspective. A qualitative case study was conducted in four health operations operators in the municipality of Belo Horizonte, Minas Gerais State. Empirical data was collected via interviews with health operators and health providers offering home care services. The results were discussed according to three analytical criteria: provision of home care and challenges to the universal right to health; supplementary health relationship with the public health system and with families; and judicialization as a way of protecting the right to home care in supplementary health programs. Home care deregulation in supplementary health programs was exposed as a challenge to the right to health because this service provision is under health operators' control. These operators develop ways to avoid judicialization, such as providing home care services as an undisclosed benefit. The service disruption caused by the private operators' unilateral decisions and the transfer of responsibility to the public health system and families affronts the user's right to care that addresses specific health conditions. In conclusion, home care in supplementary health programs is permeated by tensions that highlight the need for urgent regulation.

Keywords: Home Care; Government Regulation; Prepaid Health Plans.

Introduction

Regulation of health as a social right is relatively recent in Brazil. The promulgation of the Federal Constitution of 1988 was a milestone in national democracy; however, it raised other challenges to secure social rights. The creation and implementation of the Unified Health System (UHS) still faces challenges, especially with regard to financial resources, assignment of responsibilities within the government sectors, and the relationship between public and private subsystems.

The private health subsystem, designated Supplementary Health (SH) services, comprises health services and activities provided by private health organizations. In Brazil, SH services began their expansion in the 1970s by selling services to pension plans. Its growth intensified starting with the crisis of the government-based healthcare model and by the consolidation of the corporate-based healthcare system (Andrade et al., 2009).

The private sector has the constitutional right to provide health services as a complement to the public system and in accordance with the guidelines and principles of UHS. By defining health services and activities as socially important, the Federal Constitution assigns to the state the responsibility for their regulation, supervision, and control. This applies to all services and activities, even if their implementation is not directly executed by the government, but through contracts or agreements of either individual or corporate entities (Brasil, 1988).

It was only in 1998 that the specific regulation of SH services began, until then it was regulated only as an insurance-financial activity. The specific regulatory framework was established by Federal Law No. 9656, amended by Provisional Measure No. 2177-44 of 08/24/2001 and supplemented by Federal Law No. 9661 in 01/2000, and the latter created the National Agency for Supplementary Health (*Agência Nacional de Saúde Suplementar* - ANS). This agency, under the Ministry of Health, is responsible for the development and execution of national strategies for public regulation of the private health sector (Andrade et al., 2009; Ceccim et al., 2009). Moreover, ANS aims to promote public interests in SH, regulate sectorial health operators, including

their relationships with healthcare providers and consumers, and contribute to the development of healthcare actions at the national level.

Regulatory activities in this sector have been marked by major disagreements. In public health, there is no consensus on the importance of bringing private healthcare services closer to NHS principles. In addition, there is a strong pressure for minimal market regulation, although internationally healthcare is recognized as an inconsistent market, which requires regulation (Alves et al., 2009).

These factors explain the lethargy and inconsistencies of regulatory activities. As a consequence, SH operators are not reimbursed because of the unprofitable health procedures that are transferred to the public system. Moreover, there are neither established criteria nor cost-effective mechanisms to incorporate new technologies to the system. Regarding the latter, we continue to be guided by the market with some regulatory intervention by the National Agency for Sanitary Surveillance (*Agência Nacional de Vigilância Sanitária* - ANVISA).

In the period 2005–2009, efforts to regulate the quality of SH were intensified through the Qualification Program for Supplementary Health (Brasil, 2012) by evaluating the extent of healthcare activities and the quality of results obtained. However, usually the main focus on the effective regulation has been directed to mandatory health procedures, healthcare service charges, and more recently, the waiting time for healthcare services by healthcare providers.

As a result, we observe significant heterogeneity in quality standards of health service sectors; therefore, beneficiaries have little access to relevant information and do not receive guidance on the subject. Among the shortcomings of the regulatory process, we highlight the lack of guidelines and actions in Home Care (HC).

Previous studies (Franco and Merhy, 2008; Martins et al., 2009) have shown that, under the label of HC, health operators have included extended services that satisfy the extensive needs of beneficiaries who are not completely satisfied by the usual healthcare services, such as medical appointments, emergency care, and hospitalization. In general, high operating costs for the production of medical

and hospital procedures have triggered the provision of extended services.

Considering that HC services are neither part of the mandatory procedures nor regulated by ANS, health operators use this “umbrella,” electing criteria to include beneficiaries in HC programs, which are offered as added benefits. Healthcare operators who offer SH services are regulated only by ANVISA through Board Resolution No. 11/2006 (Brasil, 2006), which explains organizational aspects of HC, but does not establish either contracting criteria or regulatory mechanisms.

In SH services, as well as within the public system, healthcare service beneficiaries frequently file lawsuits for healthcare coverage, decrease in grace periods, unilateral termination of contracts, and unlimited hospitalization time. This is indicative of not only the health rights in dispute but also the limitations of health regulation and the absence of well-defined criteria for technological incorporation (Alves et al., 2009).

SH care models are known to be very diverse. Health operators’ regulation of contracting between beneficiaries and healthcare providers defines different formats for the establishment of healthcare. In this context, the structure of HC is based on the organization of SH services: responding to healthcare needs but concomitantly being influenced by the economic and financial market (Franco et al., 2007).

In this unpredictable territory characterized by the lack of specific regulations, rights in dispute (Souza et al., 2007), and healthcare needs not met by traditional healthcare models, we propose the study of HC practices in SH in Belo Horizonte in addition to that of the right to health.

Methods

This research is qualitative, in the form of multiple case studies, aimed to understand the reality of a specific, multidimensional, and historically situated occurrence (Lüdke and Andrew, 1986). The use of this method in social science research allows the study of the particularity and complexity of individual cases, enabling us to understand their activity in relevant circumstances (Yin, 2005). The study of qualitative cases should address four essential

characteristics: particularity (study of a particular phenomenon or situation), description (complete description of the investigated situations), heuristic (discovery or confirmation of previously existing meanings), and induction (construction of an inductive logic in understanding data) (André, 2005).

To delineate the scope of the study, an initial mapping was conducted through a structured questionnaire directed to health operators who were located or doing business in Belo Horizonte, Minas Gerais, to identify operators offering HC. In the second phase of the study, among the operators surveyed, four were selected for in-depth assessment: one operator was a self-management model, one was a medical cooperative, and the remaining two worked with group medicine. All of them provided prominent HC services within the institution and state capital.

Empirical data were obtained through interviews with health operators and private healthcare providers, in addition to selected HC coordinators, allowing a detailed study of the event. We also interviewed health professionals and HC-eligible health operator beneficiaries.

The empirical material was subjected to an adequacy standard analytical strategy, which allows the comparison of a fundamentally empirical pattern with a prognostic-based pattern (Yin, 2005), and explored these findings using three axes: HC and the challenges for universal access to healthcare, relationship with the public health system and families, and legalization to ensure the right to health in SH.

All ethical issues on research involving humans were observed. The project was approved by the Ethics Committee of the Universidade Federal de Minas Gerais, and all participants signed an informed consent form.

Results

The empirical findings allowed us to evaluate HC offered by health operators as well as the disagreements generated by deregulation in the field, challenging the idea of HC as an added benefit, which only serves the interests of health operators, at the expense of the right of access and the needs of beneficiaries.

HC and the challenge of universal access to health

The 2010 census reported a population of 2,375,151 inhabitants in Belo Horizonte (IBGE, 2013), of which approximately 1,237,111 were private healthcare beneficiaries (ANS, 2012).

The initial mapping indicated the existence of 57 health operators and providers in Belo Horizonte, of which 38 were based in the city. Among these, 28 offered HC systematically. Of the 28, 12 answered the study questionnaire, allowing us to characterize HC as shown in Table 1. We found that approximately 11,269 patients are HC-assisted by the 12 operators/providers who answered the questionnaire, which represented 0.62% of healthcare beneficiaries in Belo Horizonte.

Interviews with health operators and coordinators in HC have revealed that services are offered to the group who uses emergency and hospitalization services considerably. We identified the demands of this target population as well as the more appropriate and economically viable solutions (in terms of reduced costs with procedures, hospitalizations, medication etc.), with an aim to extend the periods of clinical stability without complication.

The requirements for HC services vary with healthcare service programs. Thus, healthcare operators determine the organization of HC according to different criteria, which implies distinct contracting criteria with health providers, suppliers, and beneficiaries. In this context, we find situations in HC that are as diverse as the monitoring and management of cases (e.g., through telephone follow-ups by the nursing staff) or regular HC by a multidisciplinary team who may transfer technological apparatus to the domicile.

In general, HC is designed preferably for patients with health problems and chronic diseases, mostly the elderly. These patients comprise carriers of chronic wounds, neuromuscular dystrophies, sequels of cerebrovascular accident, multiple traumas, Alzheimer's, chronic obstructive pulmonary disease, and cancer without therapeutic possibilities, among others.

Healthcare beneficiaries and their families believe that access to HC represents a guarantee to the right to health in situations that require prolonged

Table 1 - Supply of Homecare Services, Belo Horizonte, 2011

Organization	Year of implementation of HC	HC services provided	Profile of HC patients	HC patients
Service provider	2000	HC, domiciliary hospitalization, management of cases and domiciliary palliative care	Beneficiaries with chronic pathologies and in need of emergency services, carriers of terminal illnesses, patients accompanied after hospital discharge	2,500 patients in different services
Self-managed operator	2004	HC, management of cases and palliative care	Carriers of chronic diseases with a history of prolonged hospitalizations or re-admittances; patients following hospital discharge and with terminal illnesses	40 patients in management and approximately 15 patients in HC
Service provider	1996	Domiciliary follow-up and monitoring of groups at risk	Beneficiaries with chronic pathologies and in need of emergency services	Not informed
Group medicine operator	2000	Management of chronic patients, HC, palliative care	Elderly beneficiaries with prolonged hospitalizations, requiring continuous care, but with clinical stability	1,258 patients in different services
Service provider	1999	Domiciliary phototherapy/ pediatric and neonatal domiciliary hospitalization	Mostly patients with neuropsychomotor deficit, dependent on oxygen and ventilation, gastrectomized and tracheostomized; most bed-ridden	26 patients
Service provider	1999	Management of chronic cases, domiciliary hospitalization	Patients with chronic, neuropsychomotor and acute diseases, with clinical stability for continuity of care	Management of cases: 250 patients. Domiciliary hospitalization: 50 patients
Medical cooperative operator	2002	Administration of wound dressings, monitoring, specific interventions, palliative care, neonatal and pediatric monitoring	Patients with chronic diseases, with functional limitations, acute diseases for continuity of care, patients with partial or complete loss of autonomy, in need of differentiated care	6,000 patients
Group medicine operator	2003	HC, domiciliary hospitalization and management of cases	Patients with cardiac, neurological, respiratory, psychomotor problems, carriers of cancer and post-surgery. Costly beneficiaries to healthcare services (due to the number of hospital visits)	Average of 12 patients in domiciliary hospitalization. In HC, an average of 80 patients, with a maximum limit of 120
Self-managed operator	2005	HC and domiciliary hospitalization	Patient with complete or partial inability to move or have access to hospital facilities (chronic patients of any age, carriers of cancer, accident victims with fractures and patients with terminal illnesses)	Average of 35 patients a month
Self-managed operator	2001	Follow-up of chronic cases	Mostly elderly, carriers of multiple pathologies and who make recurrent use of emergency services and hospitalization	179 patients assisted in 5 years
Service provider	2002	Management of chronic cases, domiciliary hospitalization and management of diseases	Beneficiaries with limitations in their daily activities and difficulty to access hospital facilities	Approximately 1000 patients on follow-up

patient care, because HC is characterized by a more humane care and a closer relationship among staff, families, and patients.

Respondents from health operator #1 revealed that operator expansion, especially in the last 10 years, prompted the diversification of services in its portfolio, which has included HC as an added benefit since 1999. Initially, operators outsourced HC, but it was replaced by other options of care as it became more costly.

At the time of data collection, operator #1 offered six HC programs with distinct objectives and coverage, ranging from simple services such as administration of wound dressings in domiciles to intensive care programs involving the transfer of technological devices to the domicile. Thus, respondents have considered HC as a complement, and in some cases, a substitute for other modes of care.

In operator #2, HC was initiated in 2004 as an added benefit and comprised four categories (management of chronic patients, HC, domiciliary hospitalization, and palliative care). This added benefit is emphasized to the families as follows:

We make it clear to families that this health service is an added benefit, which is not contemplated in the contract. As such, this benefit can be undone any time, and we make it clear to families in which situations this assistance can be undone. This agreement will be made in the form of a Term of Commitment, which should be signed by the beneficiaries, and we reiterate that this benefit can be undone any time... (Interview with employee from operator #2)

In this operator, HC was regarded as an alternative to improve the quality of care while reducing costs, confirming the logic previously described in other HC studies (Silva et al., 2012, 2010; Cunha, 2007; Franco and Merhy, 2008; Rehem and Trad, 2005; Santos et al., 2011)

Operator #3 has been offering HC since 2004 as a structured program, which is part of their list of services. The implementation of the program was mainly motivated by the demands of families who might not adjust to situations demanding continuous patient care after hospital discharge. Medical assistants were also concerned with the continuity of care, and reckoned HC as a viable alternative to

shorten hospitalization time of patients who still had some functional restrictions but did not need hospitalization. This implementation was also supported when they considered an increase in hospital re-admittance and emergency care. As in other operators, HC was highlighted as an added benefit, which was not contemplated in the contract:

At the time [of admittance in home care], we talked to him [caregiver] and explained that this is not a health coverage. Some people do not realize that even though this service is not covered in health plans, it is a benefit to health operators and patients. (Interview with employee from operator #3)

HC is recognized as an alternative that is capable of qualifying care, but when offered as a benefit, it does not constitute a right ensured by the purchase of health insurance for all beneficiaries.

In operator #4, HC began in 2000 and was later expanded and modified to incorporate the current features. The creation of the program was motivated by demands from elderly patients with prolonged hospitalization, who required continuous care but had clinical stability. Health operators offered it as an added benefit and not as a contract service.

In general, operators establish eligibility criteria for the inclusion of beneficiaries in HC and restrict access to cases where the transfer of care to domiciles would allow a decrease in healthcare costs. Such delimitation of eligibility criteria for HC is a factor that deserves consideration, because it violates the principle of universal access.

The relationship between offer and demand in the right to health tends to be positive when we consider that it satisfies the health needs of specific groups. However, it is still essential to invest in other assistance modes that, in a large scale, could meet other real demands, such as the elderly population at a risk of falling sick, and groups that currently do not depend on care but are eligible for healthcare services in the operators studied, e.g., adults and younger adults at risk of diabetes and hypertension, among others.

The results of this study indicate that HC can represent an effort for the creation of innovative models of care with comprehensive and equitable practices, fostering welfare and self-sufficiency (Sena et al., 1999, 2000; Pereira et al., 2005). It can

also become a strategy for decentralization of health services, humanization of care, and coparticipation in care (Araújo et al., 2000).

Thus, HC services in SH can have a positive impact on health and quality of life for healthcare beneficiaries by incorporating new care-oriented technologies with a view of improving the current care model (Pereira et al., 2005). However, HC is a benefit and not a right ensured by a health plan, and beneficiaries are elected under operators' criteria. The analyzed criteria are centered on operators' economic interests rather than the protection of the beneficiaries' needs. This condition makes families dependent on the benefit, which is not contractually legal.

Relationship with the public health system and families

Our results revealed several factors contributing to the decreased spending on HC, including deinstitutionalization, lesser reliance on hard technology, lower risk of complications such as nosocomial infections, and reduced demand for the multidisciplinary team. Moreover, two other elements are fundamental to cost reduction: sharing patient care with families by hiring caregivers and involving families in the acquisition of medication and other supplies. The latter is possible when we consider the noncontractual nature of HC and its lack of consumer protection mechanisms.

Interviewees have reported to involve families in healthcare costs particularly when dealing with costly supplies and procedures, such as oxygen therapy. If not possible, operator auditors will evaluate the actual need of these therapies; if needed, beneficiaries are encouraged to use the public health system. As a last resort, if auditors deliberate on these therapies but the families cannot afford, health operators may provide them, granted that they are indispensable for hospital discharge.

When the patient needs oxygen, the operator may not provide it, but we attempt to obtain it through UHS, after submitting the necessary protocols and forms. If the patient needs medication for Alzheimer's, we acknowledge that the patient relies on it. There is a protocol for special medications that are distributed by the State Secretariat for

Health, and we fill other forms when requesting each medication. (Interview Manager Carrier 1)

The patient can be discharged from the hospital, but keeping the oxygen apparatus in the domicile is needed. We clarify this to the families, and if they cannot afford to rent the devices, auditors will assess the case. Some cases are forwarded to the State Secretariat for Health when treatment is within the context of pathology, and they may consent to supply the demanded oxygen. That is why, we make these assessments. (Interview Manager Carrier 4)

These findings indicate that resorting to the public health system is a key strategy for cost reduction in HC. In hospitalization, health operators take responsibility for medical provisions, which impact healthcare costs the most (Andreazzi and Baptista, 2007), whereas in HC these provisions become the responsibility of the families or the public health system.

We do not offer equipment, but we may do so in some cases for the sake of the families. We may supply oxygen therapy to patients from 15 days to a month, during which the families submit the medical case to the State Secretariat for Health; this submission process may take a while. So while the families rent the necessary equipment for patient care, the medical case will be under evaluation. I think it is really important to guide the family, clarify their role in patient care, and assure them that HC is not as complex as they imagined. (Interview with a manager from health operator #3)

Usually when patients need intensive care, a nurse will make an overall assessment in the domicile and perform a few HC measures. Afterwards, the nurse will contact us, and we will determine the resources to be provided by us or the families. (Interview with a manager from health operator #2).

These findings corroborate previous studies indicating that one of the alternatives to reduce SH costs is the transfer of healthcare expenses to families (Martins et al., 2009; Cunha and Morais, 2007), including oral medication, enteral nutrition, and basic healthcare supplies, such as diapers (Franco and Merhy, 2008).

In this context, we question the accountability of operators that pay for expensive hospital treat-

ments, including limitless admissions to intensive care units, as to whether they should also pay for HC treatments, especially to foster patient recovery and decrease nosocomial infection risks. Such questioning also addresses the need to change the current SH model because, although it offers new service options, having HC as a large-scale and innovative option, SH does not seem to derive from a new conception of care, which is intended to be more humane and accountable for the needs of beneficiaries.

We also reiterate the deregulation problem, which limits access of beneficiaries to goods and services that should have been guaranteed by law.

Judicialization as a way to guarantee the right to health in HC

The results indicated that judicialization is a mechanism that ensures the inclusion and continuity of HC in SH, and provides the needed resources for HC:

We have injunctions requesting continuity of care, besides diapers, disposable cups etc. [...] We acknowledge that we are dealing with a benefit, and not with health plan coverage... (Interview with manager from operator #1)

Besides offering HC as an added benefit, and using it as a precaution (since HC is not an acquired right), some operators adopt a “nonpublication” policy for the service as a strategy to prevent judicialization. Operator #1 avoids the term Domiciliary Hospitalization and operator #3 avoids the term Home Care, thus preventing healthcare operators from being formally responsible for all procedures and supplies, as it would be in Domiciliary Hospitalization, and avoiding creating legally contracting conditions for HC:

When requested, [doctors belonging to the health-care network] they write “home care.” We already told them that this word is banned here, because we know that it has generated so many lawsuits on healthcare operators. (Interview with manager from operator #3)

And today we do not mean that HC is here because of the way we interpreted the term hospitalization. When we reach to the families and explain this term, they understand that Domiciliary Hospitali-

zation is the same as that available in the hospital. So we do not use the term hospitalization. We give them encouragement, intravenous medication, or oxygen therapy. (Interview with HC staff from operator #1)

Judicialization entails lack of compliance to social rights, including the right to health. Especially in SH, this theme has been recurring, marked by disagreements between private interests, represented by market-oriented health plans and health as a public asset. However, creating HC regulations that define the roles of state and industry could minimize these disagreements.

In democratic and contemporary contexts, judicialization constitutes a route to file claims on contracting terms and ensure health rights signed into law, both nationally and internationally. It involves political, social, ethical, and health aspects that go beyond legal matters and public service management (Ventura et al., 2010). It is the search for rights by those who felt mistreated by the action or inaction of others (Asensi, 2010). In the case of actions that provide health-related benefits, the state is acknowledged as an agent of omission.

The universal right to health requires the establishment of accessible, transparent, and effective monitoring mechanisms, and accountability to provide essential goods and services. Therefore, those who have duties related to the right to health are accountable for the practice of their functions, identifying improvements and obstacles and warranting the necessary adjustments in health policy, along with other corrections (Hunt and Khosla, 2008).

In the case of UHS, where access of some to certain benefits undermines the access of others because of limited resources, the right to health will have positive outcomes when we face the ethical conflict between the protection of individual rights and the guarantee to collective rights (Lima et al., 2009). The conflict in SH is distinct from it and involves citizens’ right to universal access to healthcare, consumers’ right to assets, and enterprises’ right to profit.

To ensure profits, companies become unaccountable for items that are essential to proper healthcare, and reserve the right to include or exclude HC

recipients, according to distinctive criteria. Thus, the nonregulation of HC in SH represents a major challenge in protecting the rights of beneficiaries.

It is also clear that health operators may be playing an important role in the exponential growth of individualized judicial orders, beginning in the latter half of the 1990s, especially those related to diagnostic and therapeutic procedures, and health supplies, targeting the public health system itself (Ventura et al., 2010; Baptista et al., 2009).

Conclusion

The results of the study have highlighted that, in all cases studied, HC is an added benefit provided by healthcare operators to eligible beneficiaries and does not qualify as a right acquired when contracting a healthcare service, considering that it is not included in the list of procedures defined by ANS.

With this legal and institutional status, beneficiaries are subject to the rules and constraints of the operators, who justify HC as a pursuit of economic and financial objectives, which may comply with the user's needs with a more humane and relationship-based approach.

There is no publicity by the operators studied about the availability of HC, and users learn about this service only when considered eligible.

The lack of standardization in HC also influences the existence of different forms of organization of healthcare programs, which are designed to meet specific guidelines of each operator.

Therefore, we urgently need specific regulation capable of protecting beneficiaries and minimizing contract disagreements, and the incorporation of HC in the list of SH procedures, including health coverage parameters, payment, and minimum criteria to provide HC.

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