Il testo che segue sembra rompere una antica, e rigida, regola di questa Rivista, di non accettare contributi in lingua inglese: da una parte per favorire e spingere chi ha cose rilevanti da proporre a farle conoscere a livello internazionale, dall'altra per non rischiare di essere "rifugio" (non facilmente difendibile...) di tante/i aspiranti autori di altri paesi. La proposta che si è presentata questa volta, e viene pubblicata in questa rubrica di prospettive e non tra i contributi è sembrata avere una storia particolare, tanto da meritare una eccezione che conferma la regola. Un gruppo storico di personale non-medico, diretto da infermiere, e costituitosi da più di 20 anni come gruppo di ricerca in una delle aree più povere e marginali dell'Ecuador, come espressione anche di un progetto di cooperazione italiana, si è rivolto ad AIR come strumento di visibilità e comunicazione scientifica su un tema che è centrale nell'attuale dibattito internazionale sui modelli, gli attori, i ruoli dell'assistenza, e che ha avuto una sperimentazione/sul terreno lunga più di 25 anni: è possibile, e con quali risultati un sistema sanitario ed assistenziale, nel quale i bisogni delle popolazioni siano punto di partenza e snodi di organizzazione , anzitutto dal basso, e non come oggetto di pianificazioni centrali, che preferiscono soluzioni che prescindono dalla variabilità dei soggetti, e preferiscono la standardizzazione delle procedure? Pubblichiamo l'articolo in inglese per renderlo fruibile a chi ha partecipato a questa esperienza e per dare anche una visibilità più internazionale, dato che l'esperienza è stata fatta fuori dal nostro contesto. L'eco di tematiche di AIR è evidente. E forse anche è significativo fare entrare nel ripensamento che ci si è impegnate/i a fare per i 200 anni di FN una voce che ricorda/rappresenta i tanti mondi 'altri', con i quali un dialogo non sa che linguaggio scegliere. (NdR)

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The community health promoters as protagonist actors of primary health care and community empowerment: a long term field-report from 1980 to 2018

Riassunto. *I promotori di salute come attori-protagonisti delle cure primarie nel controllo delle malattie comunicabili e non comunicabili e nell'empowerment delle comunità. Esperienza e risultati di lungo periodo in aree marginali in Ecuador dal 1980 al 2018.* **Introduzione.** Nonostante il crescente riconoscimento dell'importanza fondamentale della partecipazione diretta delle comunità per assicurare un'assistenza sanitaria nelle aree periferiche delle nazioni a Medio-Basso reddito (MLIC), esperienze rappresentative di lavoro sul campo sono raramente disponibili. **Obiettivi e metodi.** Riportiamo il racconto documentato di uno spettro di progetti rivolti ai bisogni sanitari di base e specifici di comunità disperse e periferiche dell'Ecuador, un modello di MLIC, e vengono discusse le implicazioni per il ruolo e il lavoro dei promoto-

Summary. Introduction. Against the increasing recognition of the critical importance of a direct participation of community members to assure effective health care in peripheral areas of Middle and Low Income Countries (MLIC), representative field experiences of their essential role are only occasionally available. **Aims and methods.** We report a narrative, factual documentation of a spectrum of projects covering the basic and specific health needs of the disperse communities in Ecuador, a model MLIC, and discuss the broader implications of the role and performance of HPs over a long period, 1980-2018, in the project activation, implementation and monitoring. **Results.** The role of 60 HPs, with the coordination of a small core group of professionals of the Centro de Epidemiologia Comunitaria y Medicina Tro-

ri di salute (HPs) in un periodo dal 1980 al 2018, nell'attivazione, conduzione e monitoraggio del progetto. **Risultati.** Vengono documentati i principali risultati di un gruppo di 60 HPs, coordinati da un piccolo gruppo di professionisti del Centro de Epidemiologia Comunitaria y Medicina Tropical (CECOMET) e nello specifico su: malattie infettive, in particolare le malattie tropicali neglette (eradicazione di oncocercosi e framboesia; eradicazione virtuale della malaria e della strongiloidosi; eradicazione e controllo di un un nuovo focus della Malattia di Chagas; controllo della tubercolosi), salute della madre e del bambino, salute riproduttiva, ipertensione (come modello dell'emergenza di malattie croniche non trasmissibili). Le strategie e i metodi più efficaci e sostenibili sono discussi anche per la trasferibilità più generale, già parzialmente sperimentata in programmi in Bolivia, Burkina Faso, aree più povere dell'Argentina. **Conclusioni.** La disponibilità sistematica di HPs non professionali e formati dovrebbe essere una componente sostenibile e affidabile delle strategie di assistenza sanitaria e uno degli interventi mirati agli ambienti emarginati, per assicurare una concreta accessibilità al diritto umano fondamentale alla vita.

Parole chiave: Ecuador; promotori di salute; partecipazione comunitaria; primary health care; epidemiologia comunitaria; malattie tropicali neglette.

pical (CECOMET) is documented through their main achievements which include: infectious diseases and in particular Neglected Tropical Diseases (eradication of onchocerciasis and yaws; virtual elimination of malaria and of strongyloidiasis; identification and control of a new focus of Chagas Disease; control of tuberculosis), mother and child health, reproductive health, hypertension (as model of the emergence of non-transmissible, chronic diseases). The most effective and sustainable strategies and methods are discussed also in terms of their more general transferability, already partially tested in programs in Bolivia, Burkina Faso, undeserved areas of Argentina. **Conclusions.** The systematic availability of non-professional, trained HPs should be recommended as a sustainable and reliable component of health care strategies and interventions targeted to marginalized settings, to assure a concrete accessibility to the fundamental human right to life.

Key words: Ecuador; health promoters; community participation; primary health care; community epidemiology; neglected tropical diseases.

INTRODUCTION

Over the last several years, against the celebrations of the permanent validity and priority of the Alma Ata principles focused on the central role of primary health care for the effective sustainability of all health systems,[1-3] reports of international agencies and commissions as well as the consistent results of academic public health research have documented the extension and the severity of unmet needs of the marginalised populations threatened by the unabated and possibly growing impact of inequalities.[4-7]

The direct inclusion of healthcare into the broader political and even more importantly economic reshaping of the International scene (from the global burden of diseases reports starting in the Nineties, to the Millennium Development Goals in 2000, to the crisis of 2008, to the Sustainable Development Goals of 2015) has paradoxically transformed health care, from an expression of fundamental rights into a sensitive indicator of the impossible-to-bridge gap between recommendations for universal care and the inaccessibility to effective but market driven and dependent care delivery.[8-12] An inversion of value criteria according to constitutionally enforceable principles could be conceived only by increasing the investments on health personnel and community empowerment , both of which measures are recognised to require the democratisation of societies.[13-14]

This report proposes a factual survey and evaluation of a program which has been implemented over almost 40 years, in a typical marginal rural context of a country like Ecuador, which has gone through the full spectrum of the above evolutions.

Its main purpose is to document how bottom up strategies should and could be developed and maintained with program centred on the real needs of the communities, with HPs as principal actors , in close complementarity with a core group of medical and nursing personnel, in assuring flexible strategies of effective care for the burden of the whole spectrum of the problems and diseases which are typical of the epidemiological transition: from mother and child health, to classical, and specific, infectious conditions, to chronic non transmissible diseases.

CONTEXT AND METHODS

The main geographic and socioeconomic characteristics of the region of interest and of its population can be summarized as follows. The health region of Borbon, in the province of Esmeraldas in Ecuador, coincides with a territory of 5000 sqkm of the Amazonian forest, with a population which has grown from approximately 25000 to 40.000 inhabitants, 85% afro descendants, 10% Amerindian indigenous, 5% whites, dispersed over 129 villages bordering three rivers, which are the almost exclusive communication and transport routes. The socioeconomic conditions, not substantially improved over the period of observation of this report, include an 84% of poor, of whom 34% extremely poor. The health system was and is still organized with a community 20-bed hospital and 12 health posts along the rivers.

The great dispersion and isolation of the communities (Figure1) and the unavailability of institutional personnel imposed a strategy where the minimal core staff of the cooperative program (a young Italian woman medical doctor, with the support of a non-medical competence in logistics and organization, joined early on by a young Ecuadorian medical doctor) concentrated its efforts in the involvement and basic training of motivated members of the communities.

Figure 1. Areas where the communities of the project live

Progressively, over a 2-year period, a group of 60 health promoters (HPs), almost all women, was established to assure a permanent presence in the community, with the task of monitoring and caring primarily for the classical basic needs of mother and child health, and to guarantee compliance with the essential requirements of other emerging /presenting needs. With the expansion of the activities, it became clear that an effective and accountable program should also include an epidemiologically oriented data collection to register, assess, monitor and report needs, achievements, failures. This program of systematic prospective data

collection was included among the tasks of the HPs, with the coordination of a small central group whose members however were also deeply involved in the field work with the HPs. In close collaboration and with the support of international academic groups and donations, the central coordination, institutionally affiliated with the regional catholic authorities (Vicariato Apostolico) of Esmeraldas, was organized as a research unit (CECOMET, according with the Spanish acronym, Centro de Epidemiologia Comunitaria y Medicina Tropical) with a statute assuring its full autonomy of action.

RESULTS

The detailed description of the activities, the methods of intervention, the specific clinical and epidemiological results of each of the projects have been the object of ad hoc reports and publications, which are easily accessible and cannot be summarized here.[15-21] Table 1 summarizes the evolution of the projects covering the articulated spectrum of the problems which over the years were assumed as successive and parallel responsibilities of the program and provides a synoptical view of the main documented achievements.

Table 1. Main areas and model results of HPs based community interventions

A) Mother-and-child health		
Time frame	**Areas of intervention**	**Main model results**
1980-ongoing	Mother and child health: malnutrition; pregnancy and perinatal care; women reproductive health; vaginal cancer prevention	Children <5 years malnutrition prevalence: from 29% in 1984 to 3-2% since 2005. Maternal deaths: 14 cases, 1995-2000; 4 cases for each quinquennium till 2015. Since 2005, no more eclampsia-related deaths.[15-16]
B) Neglected Tropical Diseases (NTD) and other communicable infections		
1980-2009	Onchocerciasis	From 1980 to 1989, 100 communities with hyperendemic (42), mesoendemic (15), and hypoendemic (43) onchocerciasis. 1991 → mass administration of ivermectin, covering ≥85% of the population. Elimination confirmed; formal certification by WHO in 2014.[17]
1980-1998	Non-venereal treponematosis (yaws)	Clinical prevalence in 1988: 16.5%; positive serology in 36.3%. Elimination confirmed in 1998; administratively pending formal certification.[18]
1980-1999	Soil Transmitted Helminths	Sustained elimination of strongyloidiasis (from 6.8% in 1990 to 0 in 1996 and in 1999), and decreased prevalence of trichuriasis.[19]
1991-2009	Malaria	From 60/100 prevalence in 1993 to 0 cases from 2009 onward.[20]
2000-2005	Tuberculosis program in the very high risk Chachi population	Lost to follow-up: from initial 60%, to 2% in 2005, to <1% onward.[22,25]
2013-ongoing	Chagas disease	Identification, screening and control of Chagas in the geographically and culturally very isolated Awa population.[20]
C) Non-communicable diseases		
1995-ongoing	Community control of hypertension	37% prevalence in the screening of the >18yr population included in a monitoring program (with 2-4 controls/year) covering progressively the whole population: 90% follow-up compliance; 30% decrease of the fraction at higher risk (and of morbidity/mortality).[17]

The chronological sequence provides a synoptic view of the progress and of the articulation of the main projects. It is easy to recognize their different target populations and corresponding strategies of intervention. Mother and child health conditions are by definition the core focus of any community attention in the MLIC. Among transmissible infectious diseases, onchocerciasis, which represents a severe threat of blindness, was geographically restricted to a river area, where the access of external personnel cannot be assured on

a regular basis; strongyloidiasis is a life-threatening STH that had an exceedingly high prevalence in the region. Tubercolosis affecting mainly an isolated forest ethnic group was a reservoir of the disease very difficult to control without a very close long term monitoring needed to overcome the cultural resistance and the bad nutrition conditions of the group; yaws is a sparse, invalidating dermatological condition controlled through a long term integrated intervention based mainly on education allowing for a very early medical treatment and a reliable compliance. It needs a regular long term monitoring of the infected persons (with a specific threat for children), which must be accompanied by a supervised compliance with the pharmacological treatment. Malaria was an area-wide problem which disappeared through an intervention centered on the involvement of the communities in the sanitation of the contexts of life, while drugs and impregnated nets availability played a necessary but subordinate role. Hypertension was adopted as a priority among NCCD to control the specific high cerebrovascular risk and mortality in the young male African slaves descendant subpopulation, and became rapidly an educational/learning model for a population wide monitoring.

The main results obtained in the area of Chagas could be seen in the slowly progressing but successful overcome of the deeply rooted cultural traditional barriers to interventions which should imply blood sampling and long term treatment of selected individuals. All the 6 AWA communities could be included with the needed agreement of their leaders, and allowed for the first time a reliable identification of positive cases in each of the communities (Figure 2).

Some of the main activities assured by the HPs as part of their direct responsibilities in the implementation of the projects at the level of the community where they lived are shown in Table 2.

Figure 2. Distribution of HPs in the disperse areas

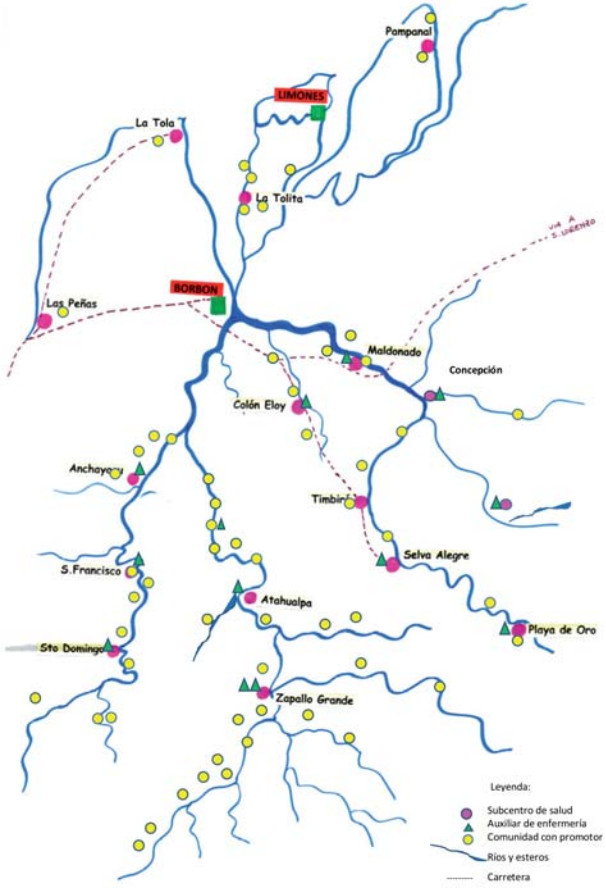

Table 2. Examples of problem-specific diversifications of roles and activities of HPs

Area of intervention	Activities implemented
Mother, child, women health	Permanent intensive, community specific participatory strategies; problem-oriented articulation of the HPs epidemiological notebook and registration (e.g. nutritional status of <5 years; pregnant/post partum women); life histories and verbal autopsy registry of all morbidity/mortality cases; referral of suspected/ at risk cases to higher care level; careful interaction with most marginal community components to document and assess/assist avoidability of socioeconomic and cultural determinants of their unfavorable life and health conditions.
Onchocerciasis, STH	Long-term run-in phases of the program, with a participating presence in communities to activate culturally adapted educational and medical interventions; very detailed registry of detection, treatment, follow up of nodules; distribution and close observation of compliance with ivermectin treatment; 100% tracing of any suspected lost to follow-up; mandatory collective participation (every 6 months) in the quality evaluation of the program. This combination of activities was also crucial in virtually eliminating strongyloidiasis from the same area.
Malaria	Focus on the importance of a mosquito-free environment, associated with field assistance in specific sanitation procedures; monitoring and reporting of each febrile case, including collection of laboratory samples; very close control of effective coverage with impregnated nets.
Tuberculosis	Active search of individuals with respiratory disorders, community training with audiovisual support and maps that indicated the most involved communities. Sputum samples sent to the laboratoy for acid fast stain. Directly observed treatment with pre-packaged doses; register of treatment and discussion of each failure.
Hypertension	Full responsibility in screening organization and implementation in the disperse communities; epidemiological surveillance with a focus on the characteristics and implications of an almost asymptomatic risk condition, and on the importance of life style conditions of risk; stratification of cases according to estimated risk level and monitoring strategy; control of compliance with the assigned schedule of follow-up; timely referral to the medical level for dubious/worsening/difficult cases ; periodical inter-communities discussion of the data of the program.

Their informal but defined and perceived role as a resource of the communities (Figure 2 indicates their distribution in the disperse areas) became well recognized and source of trust, as the result of a dedicated daily availability for the basic package of information, education and communication (IEC), implementation of preventive, therapeutic, referral, follow-up activities, data collection, under the regular and participatory supervision of the professional components of the staff. In the absence of institutional instruments for data reporting and collection, each HPs was trained and monitored to register according to well defined criteria the essential data of its activities in a dedicated notebook. These notebooks ("los cuadernos epidemiologicos comunitarios") of the HPs became a respected pillar of the increasing health awareness of the communities, as they were seen as a reliable tool for assuring a targeted continuity of the at home and collective interventions, while fully respecting the due personal privacy.

A rigorous "quality control" of the substantial compliance with the essential components of the clinical duties of the HPs and specifically of their data collection was assured at the occasion of periodical (planned and ad hoc) visits by the core staff of CECOMET. More importantly the strictly mandatory collective meetings of the HPs with the central coordination were established for a full intensive working day every month. The critical importance of these "meetings on the 22nd" (where numerical results were translated in didactical maps and graphics, Figure 3) cannot be overemphasized.

They became the vital instrument both for building a solid collective responsibility needed to make sustainable a long and not easy commitment, and for assuring a permanent learning exercise based on the highly participatory presentation, discussion, validation of all the morbidity and mortality events of the month. The methodology of "verbal autopsy"[23] applied to all major events became a powerful learning tool, as it allowed a shared awareness of the relevance of the contextual, clinical, personal components and determinants of care and of its outcomes, progressively better formulated in a precise language and terminology. The selection and the adoption of the priorities of each community for the next month assured consistency to the planning.

The progresses of the above HPs centered activities and their broader implications in terms of a sustainable and

Figure 3. Didactical map summarizing the epidemiology of maternal complications and their attributable causes for the Eloy Alfaro District, Borbon area, years 2018

accessible health organization were reported also in the publication of successive texts of community epidemiology,[22, 24-25] as well as of other materials dedicated to specifically relevant topics.[26-28] Conceived and composed as a collective work, such materials were looking for, and reached, a wider audience within, but more importantly also outside the strictly health care contexts.

The "external" validation of the originality of a HPs centered approach to provide qualified and long-term answers to the primary care needs in disadvantaged settings has represented another important result. The original project was requested to be expanded to other areas of the region in Ecuador, while the publications mentioned above received an interested attention at academic and institutional level not only in the country, but also in Bolivia and Argentina.[29-30] A similar program was activated (through also direct and reciprocal visits exchange whit "African" HPs) in Burkina Faso, while training programs for community health in Bolivia, over the last 10 years, are based on the experiences, the methodology, the epidemiological approach described above. It could be now affirmed that the best and more reliable health resource for poor and institutionally marginal settings are (also in urban areas such as Cordoba and Buenos Aires) persons who belong to and live in the communities, while professional competence and institutions act as support and co-responsible partners.[30] It is symbolically interesting that in the context of the Alma Ata celebration in Quito in 2018 the HPs based project has been formally recognized by PAHO as the best example of health and citizenship promotion.[31]

A last critical remark must be focused on the crossing of the HPs based community approach with the changes occurred in Ecuador with the initial phases of the implementation of the strategies of care prescribed by the new Constitution of the Country. As foreseen specifically in its key pertinent articles[32] a comprehensive interpretation of the universal right to health should include all aspects of life ("el Buen Vivir"). Its translation

however requires investments which coincide with the assignments of more institutionally trained personnel to a network of at least minimally equipped 'health centers/services", where essential drugs and diagnostic resources could be accessible in working days. The good relations which have been developed between most of the new state health representatives and the network of HPs have allowed an important collaboration (eg. program on Chagas epidemiology in Awa indigenous population), without however bridging the substantial gap between a system which is present and active where peoples live, and one which assures that the right to health must become accessible in specific places and times.

DISCUSSION

The inevitably too synthetic narrative report on the achievements of the community projects implemented over an uninterrupted long term period in the marginalized territories and health districts of Borbon and Esmeraldas provides an encouraging documentation that the strategies adopted have produced relevant public health results (Table 1). Across the highly diversified spectrum of settings of their actions, the central role of HPs is possibly the most consistent and original finding, which requires few comments.

Over the long period covered in the report, the projects have been conceived and realized not as separate studies, but as a progressive expression of a broad population targeted and wide plan which was nothing else but the development of the daily care required to cover concrete needs. The translation of the results into the series of publications and reports mentioned above[15-20; 24-28] documents that progressive positive results in a heavily underserved environment correspond to the compliance of the delivered care with concrete and diversified needs, more than with guidelines and protocols of intervention activated and implemented in a pre-defined time frame and according to a priori agreed and rigidly defined outcome endpoints. The long term continuity of the presence of HPs and of the core staff of the program to pursue the best possible accessibility of all the needing members of the communities to prevention and treatment coincides with the emergence and consolidation of a shared culture between the non-professional as well as professional health workers and the communities. The latters become not objects of interventions, but co-protagonists of a project where the recognition and the collaborative search for the respect of individual and collective rights to a life in dignity, remain the fundamental terms of reference, beyond the control of diseases.

Against this general background, the reasons of a protagonist role of the HPs in marginal health settings are somehow obvious. They are not an occasional or external presence. Their basic technical competences represent the bridge of knowledge, language, information which assures the timely monitoring of the needs as well as the timely referral to higher levels of competence for the problems which cannot find a ready answer locally. The amazing long term compliance with the appropriate recommended life behaviors (which are the main determinants of positive results, besides the more strictly medical interventions) corresponds to an atmosphere of trust, generated by the daily and flexible interactions needed to overcome the many barriers which must be faced to change traditional attitudes and behaviors.[34-36]

The adoption of a strategy of routine, structured data collection, controlled with the periodical evaluation and participatory interpretation of the successes and of the failures, has proved to be an indispensable and effective tool, which has strengthened the awareness and the critical self confidence of the HPs. The participatory development of the tools and of an integrated language of community epidemiology (see Figure 3 for a model of didactical presentation of quali-quantitative information) contributed greatly to give the HPs the perception of their autonomous responsibilities, always interacting with, but not hierarchically dependent from, the professional personnel.

It should be clear that the above narrative scenarios do not coincide with a reality allowing for a linear nor ideal story. The, often very tough, conflicts with the institutional representatives of the official settings of the health systems in the small and badly equipped hospitals and health centers, have been a daily experience, which imposed delays, adaptations, temporary cancellations and changes of the planned strategies. A substantial continuity and coherence could be maintained thanks to the solid support of the communities, which were experiencing difficult but rewarding improvements in the solution of their problems, and the growing perception of being subjects in their struggles for a life with less fear and more visible dignity.

CONCLUSIONS

The inevitable and due conclusion of this overview of a long, complex, ongoing story coincides with a question which is central in the present global scenarios of community and public health. What is the transferability of this experience in the contradictory conceptual and operational frameworks which characterize the present confrontations between the recognition of the priority of health rights, and the confirmation of political and economic models which are not ready nor willing to antagonize the growing expulsion of what is not financially sustainable?[37-39]

The above mentioned recent confrontation of our story (including specifically the role of HPs) in a constitutionally strong country does not allow a simplified optimistic answer. Technological and structural investments are preferred to investments targeted to increase the availability of personnel (equivalent or in coherence with HPs) in more undeserved areas. The evidences that the non medical determinants of health and life are increasingly important, do support that also a sound costs/benefit evaluation would favor a full recognition of HPs as integral components of democratic and effective health systems.

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