

3 Emad Hussein, Hala Borno, and John van Aalst

4 **42.1 Introduction**

5 Cleft congenital malformations are a major issue
6 in developing countries due to the disproportion-
7 ately high birth rates in poorer areas of the world.
8 Nearly 95 % of annual births in the world, and
9 94 % of all children born with clefts, are born in
10 developing countries (Mars et al. 2008). The eti-
11 ology of the high cleft incidence in developing
12 countries remains unclear. However, it is pre-
13 sumed to be multifactorial, due to various envi-
14 ronmental and genetic factors (Mangold et al.
15 2011). Toxin exposure during the antenatal period
16 is more likely in developing countries due to poor
17 sanitation, inadequate infrastructure, and politi-
18 cal instability (Hseih et al. 2011). For many of
19 the same reasons, malnutrition is also more likely to
20 be an issue for a pregnant woman living in the

developing world (Pelletier et al. 2011). Genetic 21
factors are also a major potential cause of birth 22
defects, because consanguineous practices are 23
generally more prevalent in developing rather 24
than in developed countries (Sandridge et al. 25
2010). 26

While the incidence of clefts in developing 27
countries is high, the resources directed toward 28
treating this global health issue are not increasing 29
(Mars et al. 2008). Consequently, the prevalence 30
of unrepaired clefts continues to grow, making 31
the need for coordinated global cleft care all the 32
more imperative. Over the past 10 years, global 33
health efforts, by both the nongovernmental 34
organizations and the private sector, have largely 35
focused on the area of infectious diseases through 36
the development and distribution of vaccines 37
and antiviral therapies (Nishtar and Jan-Llopis 38
2011). While these areas are important, a shift is 39
necessary toward recognizing the major burden 40
of noncommunicable conditions on developing 41
countries. With 80 % of noncommunicable dis- 42
eases occurring in low- and low-middle-income 43
countries, these countries are burdened by the 44
economic implications of decreased productiv- 45
ity and shortened life expectancies (Livestrong 46
2011). The realities suggest that the treatment of 47
noncommunicable conditions, such as clefts, can 48
serve as part of a larger infrastructure develop- 49
ment program. 50

The general scarcity of medical resources and 51
skilled healthcare practitioners in developing 52
countries significantly affects the ability to treat 53
patients with clefts (Mars et al. 2008). These 54

E. Hussein (✉)
Department of Orthodontics and Pediatric Dentistry,
Faculty of Dentistry, Arab American University,
P.O. Box 240, Jenin, Palestine
e-mail: emadhussein@rocketmail.com

[AU1] H. Borno
School of Medicine,
University of North Carolina at Chapel Hill,
Chapel Hill, NC, USA
e-mail: hala_borno@med.unc.edu

J. van Aalst
Division of Plastic Surgery, Department of Surgery,
The University of North Carolina at Chapel Hill,
7033 Burnett Womack Building, Chapel Hill, NC,
27599-7195, USA
e-mail: john_vanaalst@med.unc.edu

55 complex conditions require multiple, timed sur- 97
 56 geries that then require the attention of nonsurgi- 98
 57 cal healthcare providers (Abbott et al. 2011). 99

Multiple other errors in medications, length of 97
 treatment, and wound care after surgery, though 98
 not lethal, can lead to unnecessary morbidity in a 99
 trusting patient population. These risks demon- 100
 strate the importance of having medical transla- 101
 tors, or team members who speak the local 102
 language, before any attempt is made to provide 103
 surgical care in a foreign setting. 104

58 **42.2 Understanding Context**

59 Development initiatives, whether medical, eco-
 60 nomic, or structural, must be aligned with the
 61 vision of the community undergoing these
 62 changes (Gasper 1996). Therefore, prior to medi-
 63 cal intervention in a foreign setting, healthcare
 64 practitioners must understand local concep-
 65 tions of health and well-being. Simply asking
 66 the question, “What does being healthy mean in
 67 this community?” provides the starting point to
 68 implement interventions. Exploring a communi-
 69 ty’s representations of healthy living is essential
 70 to understand how the local people will approach
 71 a foreign medical team and react to the changes
 72 implemented.

73 Additionally, discovering how patients with
 74 clefts are treated within a cultural context helps
 75 the cleft care volunteer better understand his or
 76 her role within the cultural context of his host
 77 country. By extension, understanding how a cleft
 78 condition affects a patient’s daily living has impli-
 79 cations on the patient’s postoperative course.

105 **42.4 Considerations for the Next**
 106 **Trip**

107 **42.4.1 Geography**

108 When providing medical care in foreign settings,
 109 it is important to consider geography and land-
 110 scape (Blaikie 1995). Foreign medical interven-
 111 tions should be both visible and accessible to the
 112 local community. For example, if care is provided
 113 in a mountainous area, the team should ensure
 114 that hospitable roads are available for patients
 115 seeking care. Think about practicalities such as
 116 transporting essential supplies and equipment.
 117 Will there be problems with Customs? Will tar-
 118iffs need to be paid on equipment that is being
 119 transported? How will equipment be transferred
 120 from an airport to the local hospital? Can equip-
 121ment/supply safety and sterility be maintained
 122 during transit? Relief work may have unintended
 123 effects on the surrounding environment (Debrix
 124 1998). For example, creating a cleft care facility
 125 may redefine a town by expanding its population
 126 dramatically. Similar considerations need to be
 127 entertained long before the arrival of the foreign
 128 cleft care team.

80 **42.3 Foreign Physician Roles**
 81 **and Language**

82 Physicians around the world are often not treated
 83 with comparable respect to doctors from devel-
 84 oped countries (Gruen et al. 2004). Visiting phy-
 85 sicians must understand both the privileges and
 86 limitations accorded to local physicians. A visit-
 87 ing physician should understand whether or not
 88 the local community trusts physicians, what gen-
 89 der dynamics affect the patient-physician rela-
 90 tionship, and become familiar with mainstream
 91 medical practices (Verbrugge 1985).

92 Understanding the local language has serious
 93 implications for treatment (Wilson et al. 2005).
 94 Precise meaning may be lost in translation, result-
 95 ing in costly mistakes. To mistranslate a patient’s
 96 allergies or blood type can be a lethal mistake.

129 **42.4.2 Timing**

130 Cleft care is time-sensitive (Abbott et al. 2011). 130
 131 In an ideal system, patients with clefts begin 131
 132 receiving treatment as infants (Mars et al. 2008). 132
 133 However, in developing countries, most patients 133
 134 do not have that luxury and may simply wait for 134
 135 the next set of foreign practitioners. Given the 135
 136 potential complexity of cleft care, foreign provid- 136
 137 ers must (at least initially) arrange a regular 137

138 scheduled return to provide follow-up for patients
 139 who have undergone surgery. Local practitioners
 140 need to become involved stepwise in this plan of
 141 care in order to eventually perform the follow-up
 142 independently.

143 Timing of the surgical trips may also have
 144 effects on the preoperative status of patients.
 145 Traveling to perform cleft procedures during the
 146 winter months, when many infants will likely
 147 suffer from seasonal upper respiratory infections,
 148 may lead to unnecessary cancellation of cases.
 149 Travel in the Fall or Spring seasons may avoid
 150 these problems.

151 **42.4.3 Preparation**

152 Sufficient forethought and organization is critical
 153 for a successful trip (Mars et al. 2008). Engaging
 154 the local community prior to arrival is crucial in
 155 order to accomplish this goal (Murray et al.
 156 1994). Foreign medical teams can, for example,
 157 provide protocols to local staff for preparing the
 158 facilities they hope to work in and publicize their
 159 arrival in the local news in order to ensure that
 160 patients make arrangements to receive necessary
 161 care. Forethought by foreign practitioners
 162 includes taking precautions for their own health,
 163 ensuring that everyone receives necessary vac-
 164 cines and has appropriate prophylactic medicines
 165 (Hamer and Connor 2004). Preparation often
 166 entails bureaucratic arrangements, such as obtain-
 167 ing visas, temporary work permits, and Customs
 168 clearance.

169 **42.5 Interdisciplinary Care**

170 The highly interdisciplinary nature of cleft care
 171 makes this service unique. A team providing truly
 172 comprehensive cleft care includes surgeons,
 173 anesthesiologists, nurses, pediatricians, speech
 174 and language pathologists, dentists, and ortho-
 175 dontists. The importance of incorporating all of
 176 these disciplines on a trip cannot be overstated.
 177 Ideally, some of these providers will be local
 178 practitioners, helping deepen the connection
 179 between the foreign team and local community.

Reliance on local practitioners should grow as 180
 the work continues. 181

42.6 Forming Partnerships 182

Developing local partnerships helps the foreign 183
 team harness sufficient political support, develop 184
 alliances with medical facilities, and engage the 185
 community more broadly (Berke et al. 1993). In 186
 the context of political instability, partnerships 187
 may allow foreign providers access to vulnerable 188
 populations. Developing alliances with medical 189
 facilities is important in order to allow exchange 190
 of resources, decrease redundancy in services, 191
 and enable local providers to receive training 192
 from foreign providers. 193

42.7 Patient Selection 194

Volunteer cleft care teams should hold them- 195
 selves to the same high standards when operating 196
 in a developing country that they hold themselves 197
 at home. This starts with comprehensive preop- 198
 erative evaluations of patients who are surgical 199
 candidates (Kitlowski 1932). These evaluations 200
 can be facilitated when local practitioners play an 201
 active role in the screening process, making refer- 202
 als to local physicians for diagnostic tests as 203
 needed. Visiting professionals must not get 204
 caught up in the need to complete a certain num- 205
 ber of surgeries, but must maintain high safety 206
 standards; a cancellation for appropriate reasons 207
 simply means that the child's surgery can be done 208
 at a later, safer time. 209

42.8 Safe Surgery 210

Developing a "culture of safety" is paramount to 211
 overseas volunteer work. This starts with the 212
 group of foreign cleft care workers, but eventu- 213
 ally must include all of the participating local 214
 practitioners. Protocols must be instituted to pre- 215
 pare a facility for surgery, maintain count, and 216
 ensure that all necessary surgical steps are taken 217
 (Gawande 2009). Checklists have become part of 218

219 standard of care in developed countries and
 220 should be instituted on volunteer surgical trips.
 221 Surgical care should be delivered based on estab-
 222 lished protocols. However, providers should also
 223 be trained to adapt protocols when it is in the best
 224 interest of a patient (Thomson et al. 2010).

225 Setting a reasonable caseload for the trip is
 226 also an important safety measure. Limitations on
 227 resources, human capital, and time can affect
 228 safety if not properly recognized (Vincent et al.
 229 1998). Cleft teams need to recognize their limita-
 230 tions and only operate when conditions allow for
 231 maximal safety provisions to take place (Charles
 232 et al. 2011).

233 Foreign providers, and eventually the more
 234 involved local providers, need to be able to abort
 235 a surgical case when appropriate. Saying no in
 236 these settings can be very challenging for both
 237 the physician and for the patient or patient guard-
 238 ian. Patients or patient guardians may not neces-
 239 sarily understand why not receiving surgery is in
 240 their best interest. Clear communication using
 241 language that can be easily understood by fami-
 242 lies is essential. Safety is the primary argument
 243 for denying care in the setting where risks out-
 244 weigh benefits.

245 42.9 Patient Follow-Up

246 Patient follow-up is essential (Canady et al.
 247 1997). This care is generally the most immediate
 248 way to involve local providers, yet must be done
 249 with careful training during the trip in order for
 250 them to recognize and treat potential complica-
 251 tions following surgery. The capacity to take pic-
 252 tures and send them globally to foreign team
 253 members can facilitate communication about
 254 patient problems. Complications should be ade-
 255 quately recorded, and there should be a forum
 256 that allows honest discussion of the complica-
 257 tions. When foreign physicians return to the local
 258 community, patients who have previously under-
 259 gone surgery should be seen as part of the screen-
 260 ing process. Eventually, local providers should
 261 play an increasingly central role to this process of
 262 recognizing and treating complications following
 263 surgery.

264 42.10 Sustainable Cleft Care

265 Before traveling to a developing country to per-
 266 form cleft care, team members should have a
 267 vision of what sustainability in a particular loca-
 268 tion should look like. A plan for sustainability
 269 means that visiting physicians should teach more
 270 than treat, training local surgeons, nurses, and
 271 paramedical personnel the standards of cleft care
 272 (Berke et al. 1993) (Fig. 42.1). Training local
 273 practitioners sets the stage for the care to be part
 274 of a local independent entity in the future.
 275 Additionally, if local healthcare providers are
 276 able to provide adequate care, they can continue
 277 to train others and therefore increase the human
 278 capital providing cleft support in the area.
 279 Training local medical personnel also empowers
 280 the community to be self-sufficient and care for
 281 their own children.

282 Sustainability is also contingent upon sufficient
 283 funding and supplies for the care provided. Cleft
 284 care teams need to create continuous fund-raising
 285 initiatives, finding consistent ways to support the
 286 development of cleft care in the setting of inter-
 287 est. Cleft care is also dependent on supplies for
 288 multimodal therapy; therefore, seeking consistent
 289 support from supply companies can ensure that
 290 trips are successful. Many hospitals are able to
 291 donate unused or excess supplies. In addition to a
 292 steady stream of supplies, a cleft care team needs



Fig. 42.1 Nurse providing postoperative care to a child with cleft palate (Tulkarm, Palestine 2011)

293 a base facility. A physical structure that serves as
 294 the home of cleft care simplifies patient follow-
 295 up, enables storage of equipment, and serves as a
 296 base for potential research and education projects
 297 in the community.

298 A sustainable model for cleft care involves
 299 handing off leadership to local practitioners.
 300 Foreign providers have to establish metrics for
 301 recognizing local cleft team members are fully
 302 trained to provide unsupervised surgical and
 303 medical care to the local community. Discussing
 304 these metrics with local provider sets the stage
 305 for mutual recognition of independence.

306 Access to continuing education is an essential
 307 part of forming a cleft team (Davis et al. 1999).
 308 Providers, both local and foreign, need open
 309 access to fellowships, scholarships, and educa-
 310 tional materials. This provision also protects the
 311 community receiving care by helping ensure that
 312 the providers are exposed to and hence are prac-
 313 ticing the most modern approaches to treatment.

314 Another essential factor needed to make the
 315 cleft work sustainable is enhancing local volun-
 316 teerism – enabling the community to feel engaged
 317 with the work being done by the cleft team
 318 (Sturmer and Kampmeier 2003). Local volun-
 319 teerism leads to the establishment of local con-
 320 ferences, fund-raisers, and activities around the
 321 care of cleft patients. Integrating the cleft team
 322 into the society through local volunteerism will
 323 ultimately promote sustainability.

324 **42.11 Research**

325 Foreign providers developing cleft care teams in
 326 developing countries must be sensitive to the eth-
 327 ical issues regarding the conduct of research
 328 (Buchanan and Miller 2006). While research is
 329 an important process that drives innovation and
 330 helps to obtain sustainable funding for the cleft
 331 team, it can also compromise the safety and pri-
 332 vacy of patients (Hyder et al. 2004). Therefore,
 333 researchers must work closely with the local pro-
 334 viders to ensure that patients are fully protected.
 335 Research must receive institutional review board
 336 (IRB) approval from both local and foreign insti-
 337 tutions. Additionally, all participants must sign a

consent form and have the freedom to leave a 338
 study at any time and to ensure that all patients 339
 are aware of their rights in a research setting. 340

341 Research also serves as a tool for implement-
 342 ing primary care for cleft patients. In order to
 343 institute preventative care, researchers around the
 344 globe must work together, using the World Health
 345 Organization’s method of following specified
 346 Millennium Development Goals (Mossey et al.
 347 2011). A collaborative research approach will
 348 improve outcomes for patients with clefts
 349 throughout the world.

**42.12 Cleft Care in the West Bank, 350
 Palestine 351**

352 In 2006, cleft practitioners from the University of
 353 North Carolina (UNC) at Chapel Hill Department
 354 began traveling to the West Bank and Gaza to
 355 provide cleft care. Surgical trips have been sched-
 356 uled twice a year. While foreign surgeons are not
 357 available, local practitioners provide follow-up to
 358 previous patients and schedule future patients.

359 Practitioners who have participated in these
 360 trips have worked with local practitioners in order
 361 to build a sustainable cleft team. Visiting prac-
 362 titioners have trained local surgeons to perform
 363 cleft care. From the outset of these trips, the deci-
 364 sion was made not to perform any surgery without
 365 the presence of a local surgeon; this has ensured
 366 that every case is the opportunity to further the
 367 training of local practitioners. Since 2009, local
 368 surgeons have increasingly performed independ-
 369 ent repair of cleft palates; since 2010, cleft lip
 370 surgery has been done by local practitioners.

371 Local providers have been given opportunities
 372 to participate in international conferences on cleft
 373 care, attend educational seminars, and in the con-
 374 duct of IRB-approved research. The Palestinian
 375 Cleft Society, established in 2007, now with
 376 exclusively Palestinian leadership, assists in
 377 overseeing the care of Palestinian children with
 378 clefts throughout Palestine (Fig. 42.2).

379 In order to make cleft care in Palestine, and
 380 throughout the world, sustainable and glob-
 381 ally collaborative, this nascent cleft care team
 382 has partnered with both nongovernmental and

Fig. 42.2 Palestinian cleft society 2009 conference banner (West Bank, Palestine)



383 governmental organizations like the Palestinian
384 Ministry of Health, the Smile Train, Operation
385 Smile, and ReSurge.

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Uncorrected Proof

Author Queries

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Queries	Details Required	Author's Response
AU1	Please confirm the corresponding author. Also confirm the affiliation details for Hala Borno and John van Aalst.	
AU2	Please confirm the inserted citation for Figs. 40.1 and 40.2.	
AU3	Please provide complete details for Livestrong (2011)	

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