

1 **A qualitative study of patient, caregiver, doctor, and nurse views of factors influencing**
2 **lumbar puncture uptake in Zambia**

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4 Melissa A. Elafros, MD PhD¹, Clara Belessiotis-Richards, MBBS DTMH^{2,3}, Gretchen L Birbeck,
5 MD MPH DTMH^{4,5,6}, Virginia Bond, PhD^{7,8}, Izukanji Sikazwe, MBChB MPH⁹, Michelle P
6 Kvalsund DO MS^{5,10}

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8 ¹

9 Department of Neurology; University of Michigan; Ann Arbor; Michigan; 48105, USA

10 ²Department of Psychiatry, University College London, London, W1T 7BN England

11 ³Camden and Islington NHS Foundation Trust, London, NW1 OPE England

12 ⁴Department of Neurology; University of Rochester; Rochester; New York, 14642 USA

13 ⁵Department of Internal Medicine; University of Zambia School of Medicine, Lusaka, 10101
14 Zambia

15 ⁶University Teaching Hospitals, Children's Hospital, Lusaka, 10101 Zambia

16 ⁷Zambart, School of Public Health, University of Zambia, Lusaka, 10101 Zambia

17 ⁸Department of Global Health and Development, Faculty of Public Health and Policy, London
18 School of Hygiene and Tropical Medicine, London, WC1E 7HT England

19 ⁹Centre for Infectious Disease Research in Zambia; Lusaka; 10101 Zambia

20 ¹⁰Department of Neurology; Michigan State University; East Lansing, Michigan, 48824 USA

21

22 Corresponding author: Melissa Elafros, MD PhD, F2647 UH South SPC 5223, 1500 E Medical
23 Center Drive, Ann Arbor, Michigan 48109. Email: elafrome@med.umich.edu

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30 **Abstract**

31 Background: Uptake of lumbar puncture (LP) remains low in regions with high prevalence of
32 central nervous system (CNS) infections like Zambia. Efforts to improve uptake are hindered by
33 limited understanding of factors influencing LP uptake.

34 Methods: Semi-structured qualitative interviews were conducted with patients with suspected
35 CNS infection, caregivers, doctors, and nurses at the University Teaching Hospitals in 2016.

36 Questions focused on LP experiences, knowledge, the consent process, and health systems
37 barriers to LP among patients with an LP indication. Interviews were transcribed, translated to
38 English, and analyzed using a thematic approach.

39 Results: We recruited 24 adult patients, 36 caregivers of adult patients, 63 caregivers of
40 pediatric patients, 20 doctors, and 30 nurses (173 total). LP barriers arose from both
41 patient/caregivers and health providers and included community apprehensions about LP, proxy
42 (family) consensus consent practices, competing clinical demands, wariness of patient/caregiver
43 responses, limitations in consumables, and time to complete the LP. This could result in consent
44 not being obtained correctly. LP enablers included patient/caregiver perceived LP utility,
45 provider comfort with LP, and in-person counseling.

46 Conclusions: LP uptake is a complex sociocultural process influenced by patient, health care,
47 and community-level factors. Interventions to improve uptake must address multiple barriers to
48 be successful.

49 **Introduction**

50 Meningitis is the second greatest contributor to neurologic disability-adjusted life years
51 (DALYs) for the Eastern sub-Saharan African region.¹ In Zambia, meningitis mortality is higher
52 than expected for its sociodemographic index, suggesting additional factors influence
53 outcomes.¹ Among patients with symptoms concerning for CNS infection, timely completion of a
54 lumbar puncture (LP) for cerebrospinal fluid (CSF) analysis is essential to determine disease
55 etiology and guide treatment selection and duration.² Further, serial LPs are associated with
56 improved survival in cases of cryptococcal meningitis where elevated CSF pressure can result
57 in death.³ Yet, in 2011, 40% of HIV-positive Zambian adults with new-onset seizure, which could
58 be a marker of meningitis, did not have CSF collected.⁴ Low LP uptake was also reported
59 among Zambian children presenting with suspected neurologic infection from 2016-2018; similar
60 findings have been reported in other regions, including Malaysia and Pakistan.⁵⁻⁷

61 Literature examining reasons for low LP completion rates has predominantly focused on
62 patient/caregiver refusal to provide LP consent due to limited knowledge.⁸⁻¹⁰ LP-related
63 knowledge and attitude surveys performed in Asia and the Middle East among healthy adults or
64 relatives of children with febrile seizures suggest that understanding of LP is limited.^{9,11,12} In
65 northern Zambia and Botswana, adults reported concern that LP can cause death, but the
66 relationship of this belief to LP uptake was not assessed.^{13,14} Health care workers (HCWs) have
67 acknowledged heightened fear of death associated with LP in low-to-middle-income countries
68 (LMICs), possibly as a result of misattribution of high mortality from opportunistic infections.¹⁵
69 However, there is a lack of literature understanding this fear. Additionally, factors associated
70 with LP uptake in pediatric patients in sub-Saharan Africa has not been evaluated.^{13,14}

71 A recent study by Saylor et al found that LP uptake varied between three facilities in
72 Zambia, highlighting the importance of other factors besides patient/caregiver perceptions
73 contributing to the successful completion of an LP in a patient with a clinical indication for CSF
74 collection (i.e. LP uptake).¹⁶ These include HCW recognition of LP indication, insufficient time to

75 deliver information about LP and obtain informed consent, HCW perceptions surrounding LP
76 safety and acceptance, procedural knowledge, and other health systems factors such as the
77 availability of consumables needed to obtain or analyze CSF.¹⁵ The importance of these factors
78 is evident in CSF studies being recently added to the WHO's essential in vitro diagnostics list
79 intended to guide worldwide laboratory supply procurement.¹⁷

80 Unfortunately, the impact of these real and perceived barriers on LP uptake remain
81 poorly elucidated. Few studies have examined LP barriers from the perspective of HCWs.¹⁴
82 Doctors in Botswana reported confusion about LP contraindications, but the impact of this on
83 willingness to request or complete the procedure was not elucidated.¹⁴ Further, despite playing
84 an integral role in patient and caregiver education, nurses' perspectives have not been
85 characterized. Attempts to improve LP uptake are likely to be ineffective until the factors
86 contributing to this diagnostic gap are fully explored. Therefore, we conducted semi-structured
87 interviews of patients with suspected meningitis, their caregivers, doctors, and nurses to
88 characterize inpatient LP barriers.

89

90 **Materials and methods**

91 **Study design and participants**

92 We recruited participants from the University of Zambia's University Teaching Hospital
93 (UTH) Adult and Children's Hospitals in Lusaka by going bed-to-bed in the adult and pediatric
94 emergency, admission, and medical wards between April 4 and July 19, 2016. Eligible patients
95 included individuals of any age presenting with symptoms concerning for CNS infection. If the
96 patient was below the age of 18 or unable to make medical decisions, a bedside caregiver was
97 approached for participation. We opted for this approach as caregivers often serve as proxies
98 for patient consent in this setting. Only one caregiver was interviewed per patient. Patients and
99 caregivers were interviewed by nurses in the language of their choice. Eligible HCWs included
100 doctors and nurses providing care on wards where patients were recruited. Nurses were

101 interviewed by a nurse, while doctors were interviewed by a visiting physician. All interviews
102 were conducted in a private room adjacent to the ward and, upon completion, participants were
103 provided 30 Kwacha (~6 USD at the time) for transportation costs.

104

105 **Procedures**

106 Semi-structured interviews were conducted as part of a larger mixed-methods study of
107 LP knowledge, attitudes, and beliefs. Qualitative responses were hand transcribed during the
108 interview. Audio recording was not conducted due to concern it may limit participant candor.
109 Within 24 hours of the interview, responses were translated to English, as needed, verified for
110 accuracy by peer review among interviewers, and entered electronically into Microsoft Excel.

111

112 *Patients & caregivers*

113 Participants were asked if they knew someone who had undergone LP. Among those
114 that did, probes included their relationship to the individual and LP outcome. Patients and
115 caregivers were asked how much they felt they knew about LP. Follow up questions focused on
116 the purpose of LP, benefits, and risks of the procedure. They were asked whether patients have
117 the right to decline LP, risks to the patient if a LP were refused, and alternative procedures that
118 could be done if a LP was refused. Probes sought to elucidate the difference between pre-
119 admission LP knowledge and information shared HCWs during admission. Patients/caregivers
120 were asked to describe their concerns about LP. They were asked who they discussed the
121 procedure with when deciding whether to consent and why they opted to consent to or decline
122 LP. For each patient/caregiver, LP uptake was determined. This was defined as successfully
123 performing a LP for CSF collection in a patient with an indication for the procedure.

124

125 *Doctors & nurses*

126 HCWs were asked to describe the purpose of LP, risks and benefits, and alternative
127 procedures if an LP is refused. They were asked to detail risks of not performing an LP and
128 whether patients/caregivers had a right to refuse. Probes helped clarify which information they
129 regularly shared with patients/caregivers when discussing LP. Lastly, HCWs were asked to
130 describe other circumstances, besides refusal, that result in poor LP uptake.

131

132 **Data analysis**

133 Analysis was conducted using a modified thematic approach. Two coauthors
134 independently reviewed the data multiple times to understand meaning and identified significant
135 phrases that were then restated in general terms to be used as themes. Responses were then
136 coded, and themes were organized into broader categories. Key quotes exemplifying themes
137 were identified and provided to two additional coauthors who were asked to group the quotes
138 into themes. Findings were then compared and discussed until consensus on the themes and
139 categories were achieved. To determine whether themes differed between the Adult and
140 Children's Hospitals, responses were examined by hospital. All authors agreed with the results
141 and chose the highlighted quotations. The data underlying this article will be shared on
142 reasonable request to the corresponding author.

143

144 **Ethical approval**

145 Written, informed consent was obtained from participants in the language of their choice
146 (English, Nyanja, or Bemba). Ethical approval was obtained from the University of Zambia's
147 Biomedical Research Ethics Committee and Michigan State University Biomedical Institutional
148 Review Board. Interviews were conducted at a time convenient for the participant and
149 interviewers were trained to recognize participant distress and medical emergencies. Interviews
150 were halted if either of these situations arose.

151

152 **Results**

153 *Description of study participants.*

154 Our sample consisted of 24 adult patients, 36 caregivers of adult patients, 63 caregivers
155 of pediatric patients, 20 doctors, and 30 nurses (173 participants in total). 58 participants were
156 male, and most were age 24-48 years. Among patients and caregivers, 69 had completed at
157 least some secondary education. 22 had formal employment whereas 38 were informally
158 employed.

159
160 LPs were performed on 67 of 123 interviewed patients/caregivers. Seven themes
161 emerged that could be grouped into two thematic categories – LP barriers and LP enablers.
162 Themes were also grouped according to actors involved, as shown in Figure 1.

163

164 ***LP barriers***

165 *Community apprehensions*

166 While most knew that an LP entailed removal of fluid from the back, there was
167 consensus that there was a lack of knowledge about LP in the community. Despite this, most
168 patients/caregivers knew a relative or acquaintance who had an LP and had a poor outcome.
169 Patients/caregivers drew on these prior experiences to inform their decision to consent or
170 decline LP. Death and paralysis were the most cited reported outcomes of LP. “I fear that my
171 child might die because my father died after the procedure” (pediatric caregiver). Death was
172 specifically attributed to timing of the procedure – if done too late or when the patient was not
173 strong enough. Paralysis was attributed to the position the patient was placed in during or after
174 the procedure. Fear of death or paralysis was cited by all adult patients/caregivers and 12
175 pediatric caregivers as the reason for LP refusal. However, patients and caregivers felt that
176 patients now were more likely to survive LP than in the past and attributed this to a new
177 technique for performing the procedure or, in some instances, to “God’s will”.

178 Multiple physicians said that, because LP gained prominence when no treatment was
179 available for HIV, the community associated it with the significant mortality of that era. HCWs
180 were cognizant of the impact that community apprehensions have on patient/caregiver
181 willingness to undergo LP. Patients may rescind consent at the urging of other
182 patients/caregivers on the ward if too much time passes between consent and LP completion.
183 Physicians also reported that community apprehensions influenced which patients they sought
184 to LP. Recalling patients on whom an LP was clinically indicated but not done due to the
185 severity of illness on presentation, they recollected their concern that other patients and
186 caregivers on the ward would see that patient's demise as evidence that LP kills. "If a child is in
187 the terminal stage, then it is appropriate not to do it as it will reinforce the belief of death"
188 (pediatric physician).

189

190 *Proxy family consensus for LP consent*

191 HCWs and caregivers noted that being asked to consent on the patient's behalf resulted
192 in psychological stress that impacted decision-making abilities. "It's hard to make a decision
193 alone unless you consult other family members" (adult caregiver). Caregivers often consulted
194 extended family members, often citing elder male relatives or grandmothers, and the decision to
195 consent to LP was made by consensus. "I think the decision comes from others because they
196 don't want to take responsibility; they feel the family will blame them" (adult physician). Family
197 consensus was a major barrier to care as consulted relatives often did not reside in Lusaka.
198 Among those interviewed who had not yet consented to an LP, seven percent of patients and
199 caregivers were awaiting additional family discussion to consent. One pediatric caregiver
200 refused to consent without family consensus because "if a big problem occurs, I will be blamed."
201 When the patient was sufficiently well to make his/her own medical decisions, family consensus
202 may overrule patient wishes. "The father and uncle to the patient refused after the patient
203 consented and doctors could not carry out the procedure" (adult nurse).

204 While HCWs generally respected this decision-making process, it was a source of
205 significant frustration. “They give me a headache. Sometimes you spend a long time discussing
206 it and then people say no” (pediatric physician). Consent was most often provided verbally.
207 Physicians did not obtain written consent as this was not the norm for procedures and they did
208 not want to further “mystify” LP. However, they formally documented refusal in the medical file.
209 HCWs rarely considered LP refusal as an opportunity to educate or counsel patients/caregivers.

210

211 *Competing clinical demands*

212 Physicians reported insufficient time to adequately counsel patients about LP
213 apprehensions. Those that did not counsel decision-makers modified their consent process in
214 hopes of obtaining consent more rapidly. They recalled minimizing or omitting risks during the
215 consent process to reduce the likelihood of LP refusal. “I told them, I am going to do a lumbar
216 puncture and it’s safe” (adult physician). HCWs caring for adult and pediatric patients recalled
217 instances where the consent process was overlooked entirely due to concern that protracted
218 discussions would impact patient care. This approach to not-so-informed consent often resulted
219 in caregivers feeling as though they had little information about the procedure even after it had
220 been completed. Sixteen percent of the patients/caregivers interviewed who had yet to consent
221 to or decline LP indicated they were waiting for more information from HCWs. Indeed, 25% of
222 patients/caregivers who refused LP did so because of lack of information. Multiple caregivers,
223 more frequently of adult patients, were told to consult relatives for consent without receiving
224 information about the utility of LP.

225 In addition to insufficient time to counsel patients, HCWs identified further clinical
226 barriers to LP uptake. These included: the desire to consult other physicians about the need for
227 LP, insufficient time to perform the procedure, inability to locate consumables such as CSF
228 tubes, or inability to locate the patient after he/she has moved to a different ward. A few
229 physicians highlighted the need to obtain a computed tomography (CT) scan before performing

230 an LP which would further delay the procedure. Even if an LP is completed, HCWs noted that
231 CSF may not be obtained (“a dry tap”) or insufficient sample would be collected, resulting in a
232 need to repeat the procedure.

233

234 **LP enablers**

235 *Perceived utility of LP*

236 Patients and caregivers frequently cited the need for a diagnosis to obtain correct
237 treatment as justification for agreeing to LP. “It helps the doctor give the right medication after
238 seeing the results” (adult patient). Adult patients and caregivers more often reported this than
239 pediatric caregivers. The informed consent process may have played a role as multiple HCWs
240 in the adult hospital mentioned this as part of their consent process. “We tell them that a proper
241 diagnosis will not be reached if they refuse” (adult nurse). LP was also seen to shorten the
242 duration of admission. “One might stay long because the doctors won’t know what they are
243 treating” (pediatric caregiver).

244 Worry about the patient’s health and severity of illness were cited reasons for agreeing
245 to LP. Interestingly, some caregivers declined consent due to concern that the patient was too
246 weak and indicated that they would reconsider once the patient becomes stronger. Adult
247 patients often presented after a protracted illness at home and LP was often reconsidered later
248 as a last resort. “We consented because the patient was getting worse, so we wanted to know
249 the cause” (adult caregiver). While caregivers may be more amenable to LP later in the
250 admission, HCWs often viewed this as too late to impact care. “I’m never comfortable doing LP
251 in someone who is about to die as I think it speeds it [death] up and won’t change anything”
252 (adult physician).

253

254 *Perception of HCW comfort with LP*

255 Confidence in the technical capacity of the treating physician was an enabling factor for
256 LP uptake among some patients/caregivers. “I had nothing to worry, because I knew the doctors
257 wanted something best for me,” (adult patient). Patients and caregivers often noted that
258 complications only developed if the procedure was done by an unexperienced clinician. HCWs
259 shared the concern that some physicians were not sufficiently trained to perform LP. While
260 endorsing confidence in their ability to perform LPs, some doctors reported incorrect knowledge
261 about LP contraindications that limited their willingness to perform LP. No doctor or nurse
262 reported dissuading a patient/caregiver from consenting to an LP, yet some were less likely to
263 agree to an LP themselves or their relative if requested by a physician. “No, I would not do it [an
264 LP on myself] and, no, I would not advise it because I am not comfortable with the expertise of
265 most doctors” (adult nurse). For some, this reluctance was reinforced by concern that LP
266 caused iatrogenic infections. “Sterility is often not observed so you can introduce infections into
267 the sterile CSF” (pediatric physician).

268

269 *In-person counseling*

270 HCWs felt they were more likely to obtain LP consent if they allowed for multiple
271 conversations and provided a simple explanation of the procedure. Physicians would
272 occasionally capitalize on the communal nature of the wards and use other patients as
273 examples of individuals who had an LP without complication. Caregivers also used fellow
274 patients for guidance. “I consulted a lady who is also nursing her sick daughter within the ward
275 who advised me that, even her, she underwent lumbar puncture, and nothing happened to her”
276 (pediatric caregiver). All participant groups cited a need for further education about LP and
277 frequently referred to in-person HIV sensitization efforts as a well-developed educational
278 intervention. However, in-person counseling alone was not enough to ensure LP uptake. “We
279 were given all of the information but, as a family, we preferred blood tests before LP” (adult
280 caregiver).

281

282 **Discussion**

283 LP uptake is a complex sociocultural process involving patients, their families and
284 community, and the health care system and its workers. By interviewing 173 patients,
285 caregivers, doctors, and nurses, we identified multiple themes that influenced LP uptake. These
286 included apprehensions about death and paralysis, the need for proxy family consensus, and
287 wariness of HCWs in time-limited and resource-challenged settings to obtain consent, deliver
288 counselling and perform LP correctly. However, there was an indication that LP attitudes were
289 now more positive amongst patients/caregivers, particularly if prior LP experiences were
290 positive, HCWs were perceived as experienced, and patient/caregivers were counselled.

291 Perceptions of a heightened risk of death and paralysis were common among
292 patients/caregivers and HCWs were wary of reinforcing this association by performing LP when
293 patients were extremely ill. Concerns about LP-related risks have been commonly reported in
294 our patient population¹⁸ as well as elsewhere in Africa, Asia, and the Middle East, and have been
295 associated with increased LP refusal by patients and their caregivers.^{8-10,19} In this study, these
296 attitudes were a result of prior experiences with LP among seriously ill individuals as well as
297 limited understanding of the procedure.

298 The decision to consent to LP requires patients/caregivers to weigh the perceived risks
299 of death and paralysis against possible benefits that were frequently unclear to participants.
300 Health literacy in Zambia is limited²⁰ and, while our data suggests that LP-related fears can be
301 overcome as part of the informed consent process, HCWs may view consent as a barrier to
302 time-sensitive care, particularly in the context of limited resources. Physicians often limited
303 education about LP to expedite the consent process. Unfortunately, lack of education was cited
304 as a reason for refusal and dissatisfaction among patients and caregivers. Task-shifting LP
305 education and consent from physicians and nurses to dedicated patient educators may be one
306 way to address education needs and overcome community misconceptions. An intervention

307 such as a bedside video, could be one way to improve LP education among patients and proxy
308 decisionmakers.²¹ Temsah et al found that video-based counseling similarly improved LP-
309 related knowledge among parents of children obtaining outpatient clinical care when compared
310 to routine in-person counseling.²² However, video-based counseling was also associated with
311 increased perception of LP-related risks than routine in-person counseling.²² This may
312 inadvertently increase LP refusal, although this was not assessed.

313 Adding to the burden associated with the LP-consent process is the need to obtain
314 consensus among multiple proxies for consent. In Zambia, there is not a legal precedent for
315 proxy medical decisions and, as a result, HCWs must quickly identify decision makers before
316 the consent process can begin. This can be particularly challenging when a family's preferred
317 proxies cannot be reached by phone or cannot travel to provide consent. Family and community
318 involvement in informed consent for clinical research has been described in multiple African and
319 Asian settings.²³⁻²⁵ As in Nigeria, where this approach is seen as a safety net for community
320 members, adopting consent practices that expedite biomedical care at the expense of proxy
321 involvement may further isolate patients and caregivers during a highly stressful time.²⁶ Calls to
322 standardize informed consent practices in this setting should consider the role of family and
323 community in decision-making.^{14,26} Further, near universal multi-proxy family consent among our
324 study population suggests that an intervention targeting just the bedside caregiver may have
325 limited impact on increasing LP uptake as that caregiver may lack authority to make decisions.

326 This study identified health systems factors that contribute to poor LP uptake in our
327 setting, including difficulty obtaining the appropriate consumables for the procedure and tracking
328 patients if they are relocated during admission. These logistical barriers hinder LP uptake
329 among patients who have already consented to the procedure and, until they are addressed,
330 may deter physicians from proposing LPs on subsequent patients. If this is the case, physicians
331 may be inadvertently reinforcing the belief that LPs are not necessary to diagnose meningitis
332 and, therefore, limiting patient and caregiver demand for this procedure. Additional health

333 systems barriers to LP uptake could include lack of laboratory reagents for the appropriate
334 investigations and physician confidence in CSF results, though these were not spontaneously
335 raised by HCWs and should be examined in future studies.

336 Adult patients and their caregivers also reported presenting late to biomedical care for
337 meningitis symptoms. As one of the drivers behind LP refusal was concern that the patient was
338 too weak for the procedure, earlier referral for biomedical care may improve LP uptake as well
339 as outcomes. Future studies should examine patient and caregiver understanding of meningitis
340 as well as care sought in the community before up-referral to a tertiary institution.

341 This study was conducted at the nation's largest tertiary care center in an inpatient
342 setting. The barriers to LP uptake may differ in rural facilities where the access to neurologic
343 expertise is often more limited. However, HCWs in this setting may be more familiar to patients
344 and their families and, as a result, may be better positioned to facilitate multi-proxy consent to
345 improve LP uptake. Further, there may be additional barriers to LP in an outpatient setting
346 where factors, such as access to a procedure room, post-LP care, and laboratory diagnostics,
347 may be a concern.

348

349 **Conclusions**

350 While patient and caregiver refusal to provide consent is often cited as the most salient
351 barrier to LP completion, barriers to LP uptake are complex and reinforced by patient/caregivers
352 and health care workers, in a cycle of community apprehensions and family consensus
353 influencing health care workers and making them wary of obtaining consent correctly and of
354 performing LP themselves. This is further exacerbated by limited resources and infection control
355 issues. However, there was shift in patient/caregiver apprehensions with usefulness, medical
356 expertise, and counseling countering concerns. Interventions to improve LP uptake in low
357 resource settings must be multifaceted, include patient, caregivers and health care workers,
358 target barriers at all levels, and build on enablers.

359

360 **Authors statements**

361 *Author's contributions:* MAE and MPK conceived the study; MAE, GLB, and MPK designed the
362 study protocol; MAE and CB carried out data collection; MAE, CB, MPK, and IS carried out
363 analysis. All authors assisted with interpretation of these data. MAE and GLB drafted the
364 manuscript; all authors critically revised the manuscript for intellectual content. All authors read
365 and approved the final manuscript. MAE and MPK is the guarantor of the paper.

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375 work.

376 *Ethical approval and consent to participate:* Written, informed consent was obtained from
377 participants in the language of their choice (English, Nyanja, or Bemba). Ethical approval was
378 obtained from the University of Zambia's Biomedical Research Ethics Committee and Michigan
379 State University Biomedical Institutional Review Board.

380 **Figure 1: Factors influencing LP completion**

381 **References**

- 382 1. Collaborators GBDM. Global, regional, and national burden of meningitis, 1990-2016: a
383 systematic analysis for the Global Burden of Disease Study 2016. *Lancet Neurol* 2018; **17**(12):
384 1061-82.
- 385 2. Gudina EK, Tesfaye M, Wieser A, Pfister HW, Klein M. Outcome of patients with acute
386 bacterial meningitis in a teaching hospital in Ethiopia: A prospective study. *PloS one* 2018;
387 **13**(7): e0200067.
- 388 3. Rolfes MA, Hullsiek KH, Rhein J, et al. The effect of therapeutic lumbar punctures on
389 acute mortality from cryptococcal meningitis. *Clinical infectious diseases : an official publication*
390 *of the Infectious Diseases Society of America* 2014; **59**(11): 1607-14.
- 391 4. Sikazwe I, Elafros MA, Bositis CM, et al. HIV and new onset seizures: slipping through
392 the cracks in HIV care and treatment. *HIV Med* 2016; **17**(2): 118-23.
- 393 5. Herbert G, Ndiritu M, Idro R, Makani JB, Kitundu J. Analysis of the indications for routine
394 lumbar puncture and results of cerebrospinal fluid examination in children admitted to the
395 paediatric wards of two hospitals in East Africa. *Tanzan Health Res Bull* 2006; **8**(1): 7-10.
- 396 6. Imamba A, Kalima P, Kwenda G, et al. Aetiology of Encephalitis and Meningitis in
397 Children Aged 1-59 Months Admitted to the Children's Hospital, Lusaka, Zambia. *Medical*
398 *Journal of Zambia* 2019; **46**(2): 81-9.
- 399 7. Ling SG, Boey CC. Lumbar puncture refusal in febrile convulsion. *Singapore medical*
400 *journal* 2000; **41**(10): 485-8.
- 401 8. Narchi H, Ghatasheh G, Al Hassani N, Al Reyami L, Khan Q. Why do some parents
402 refuse consent for lumbar puncture on their child? A qualitative study. *Hospital pediatrics* 2012;
403 **2**(2): 93-8.
- 404 9. Acoglu EA, Oguz MM, Sari E, et al. Parental Attitudes and Knowledge About Lumbar
405 Puncture in Children. *Pediatric emergency care* 2018.

- 406 10. Ahmed M, Ejaz M, Jahangeer A, et al. Frequency and Associated Factors of Parental
407 Refusal to Perform Lumbar Puncture in Children with Suspected Central Nervous System
408 Infection: A Cross-sectional Study. *Cureus* 2019; **11**(9): e5653.
- 409 11. Borhani-Haghighi A, Rezaei R, Etemadi S, Ghaem H, Shariat A. Knowledge and
410 attitudes of Iranian patients with regard to lumbar puncture. *Neurosciences (Riyadh)* 2009;
411 **14**(4): 360-3.
- 412 12. Farag E, Husain E, Fathy H, Shawky A. Perceptions and Attitudes towards Lumbar
413 Puncture (LP) among Parents in Kuwait. *Kuwait Medical Journal* 2009; **306-309**.
- 414 13. Hampande L. Attitudes and Determinants of Lumbar Puncture Acceptability Among
415 Caregivers at Three Hospitals in Zambia: University of Zambia; 2009.
- 416 14. King MB, Rweggera GM. An audit of consent practices and perceptions of lumbar
417 puncture, Botswana inpatient setting experience. *African Journal of Emergency Medicine* 2015;
418 **5**(2): 66-9.
- 419 15. Thakur KT, Mateyo K, Hachaambwa L, et al. Lumbar puncture refusal in sub-Saharan
420 Africa: A call for further understanding and intervention. *Neurology* 2015; **84**(19): 1988-90.
- 421 16. Saylor D, MA E, D B, et al. Factors associated with lumbar puncture performance in
422 Zambia. *Amer J Trop Med Hygiene* 2021: in press.
- 423 17. WHO. The selection and use of essential in vitro diagnostics: report of the third meeting
424 of the WHO Strategic Advisory Group of Experts on In Vitro Diagnostics, 2020 (including the
425 third WHO model list of essential in vitro diagnostics). Geneva: World Health Organization,
426 2021.
- 427 18. Elafros M, Belessioitis-Richards C, Birbeck GL, et al. Lumbar Puncture-Related
428 Knowledge, Attitudes, and Practices among Patients, Caregivers, Doctors, and Nurses in
429 Zambia. *Am J Trop Med Hyg* 2021; **104**(5): 1925-31.
- 430 19. Wong S, Yeoh A, Ooi T, C.S. L. Parents Views of Lumbar Puncture In Children.
431 *Malaysian Journal of Paediatrics and Child Health* 2010; **16**(2): P19.

- 432 20. Schrauben SJ, Wiebe DJ. Health literacy assessment in developing countries: a case
433 study in Zambia. *Health Promot Int* 2017; **32**(3): 475-81.
- 434 21. Kwizera R, Sadiq A, Ndyetukira JF, et al. Impact of community engagement and social
435 support on the outcomes of HIV-related meningitis clinical trials in a resource-limited setting.
436 *Res Involv Engagem* 2020; **6**: 49.
- 437 22. Temsah MH, Al-Eyadhy A, Alsohime F, et al. Effect of lumbar puncture educational
438 video on parental knowledge and self-reported intended practice. *Int J Pediatr Adolesc Med*
439 2021; **8**(2): 112-6.
- 440 23. Malik A. Physician-Researchers' Experiences of the Consent Process in the
441 Sociocultural Context of a Developing Country. *AJOB Primary Research* 2011; **2**(3): 38-46.
- 442 24. Specker Sullivan L. Dynamic axes of informed consent in Japan. *Soc Sci Med* 2017;
443 **174**: 159-68.
- 444 25. Kengne-Ouafo JA, Nji TM, Tantoh WF, et al. Perceptions of consent, permission
445 structures and approaches to the community: a rapid ethical assessment performed in North
446 West Cameroon. *BMC Public Health* 2014; **14**: 1026.
- 447 26. Jegede S. African Ethics, Health Care Research and Community and Individual
448 Participation. *Journal of Asian and African Studies* 2009; **44**(2): 239-53.
- 449