

1 **Experiences of cervical cancer survivors in Chitwan, Nepal:**
2 **a qualitative study**

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14 **Abstract**

15 **Introduction**

16 Cervical cancer is a global leading cause of morbidity and mortality. The majority of cervical
17 cancer deaths occur in developing countries including Nepal. Though knowledge of cervical
18 cancer is an important determinant of women's participation in prevention and screening for
19 cervical cancer, little is known about this topic in Nepal. This study explores the experiences of
20 cervical cancer survivors and assesses the attitude of family and community towards it and
21 stigma related to this disease in Bharatpur, Nepal.

22

23 **Methods**

24 The study design is qualitative methods involving two focus-group discussions. A total of 17
25 cervical cancer survivors were selected purposively from Chitwan. All qualitative data were
26 transcribed and translated into English and were thematically analyzed.

27

28 **Results**

29 Majority of the participants had scant knowledge about cervical cancer, its causative agent,
30 showed less cervical cancer screening, delayed healthcare-seeking behavior despite having
31 persistent symptoms before the diagnosis. The main reasons identified for not uptaking the
32 cervical screening methods are an embarrassment and having no symptoms at all. Most of them
33 endured social stigma related to cervical cancer in the form of physical isolation and verbal
34 abuse.

35

36 **Conclusions**

37 There is an urgent need for interventions to make women and the public aware of cervical cancer
38 and launch effective health education campaigns, policies for cervical cancer prevention
39 programs. This implementation can save the lives of hundreds of women and help them avoid
40 going through all the negative experiences related to cervical cancer. More studies are required
41 to gain the perspectives, knowledge, experiences, and attitudes of cervical cancer survivors to
42 add to the research.

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47 **Introduction**

48 Cervical cancer is the second most common cancer in females from low-to-middle-income
49 countries. Around 310,000 deaths occur annually due to cervical cancer [1]. Human
50 papillomavirus (HPV) infection is the major cause of cervical cancer. Although most cases of HPV
51 will resolve on their own, persistent infection with certain types of HPV (types 16 and 18) on the
52 cervix can lead to precancerous lesions that can progress to cervical cancer [2]. Nepal has a
53 population of 10.1 million women aged 15 years and older who are at higher risk of acquiring
54 cervical cancer. Cervical cancer is the most frequent cancer among women between 15-44 years
55 of age and it also ranks as 1st most frequent cancer among women in Nepal. According to the latest
56 data around 1928 women die yearly out of a total of 2942 women who are diagnosed with cervical
57 cancer yearly in Nepal [3].

58 Early detection of HPV infection through the utilization of Papanicolaou (Pap) testing has been
59 shown to decrease rates of cervical cancer. Because of restricted access to the health care facility
60 and limited knowledge about the preventive techniques for cervical malignancy, the greater part
61 of the women in Nepal has never had a pap test in entire life. Women have reported a lack of
62 knowledge of Pap tests, limited health care facilities, lack of time and money, logistics barriers,
63 and lack of social support as obstacles to receiving regular Pap tests. Since majority of people with
64 stage 1 cervical cancer is cured by therapy, it is significantly important to focus on the methods to
65 improvise the quality of life of such patients. The five-year survival rate for cervical cancer is
66 around 68%, in developed countries, but is very less in developing countries [4].

67 Females diagnosed with cervical cancer in Nepal often face many difficulties associated with
68 cancer itself, cancer treatments and their side-effects, social understandings, and monetary

69 constraints, among others. With a very strong association of cervical cancer with sexual practices
70 in women, cervical cancer has a very strong impact on the quality of life of cancer survivors. Social
71 shame and the absence of satisfactory information concerning the improvement of the cervical
72 disease have supported a low quality of life in Nepal. Besides, cervical cancer patients have been
73 found to have more terrible personal satisfaction scores when contrasted with everyone as well as
74 when contrasted with other gynecological malignancy survivors [5].

75 A very minimal subjective investigation has been done to draw out the experience of the
76 malignancy survivor in Nepal. The objective of the study is to understand how a survivor of
77 cervical cancer and their caregivers understood, experienced, and were impacted by stigma as
78 well as their perspectives on how to measure and intervene to reduce this stigma. This study will
79 help design appropriate interventions and uplift the lifestyle of a cervical cancer survivor, hence
80 accelerate the achievement towards Sustainable Development Goals.

81

82 **Methods**

83 **Study design and data collection**

84 The qualitative research design using focus group discussion (FGD) was used to explore the
85 experiences of a cervical cancer survivor. Two FGDs were conducted, consisting of 8 members in
86 one and 9 members in the other. The study was conducted from January 2019 to October 2019.
87 An interview guide was prepared by an expert panel of faculty. The questionnaire consisted of
88 open questions regarding personal experiences with cervical cancer, perceptions of what might
89 have caused their cervical cancer, experience with any symptoms, Pap screening, diagnosis, and

90 treatment, and if there were any barriers experienced cervical cancer screening. FGD was
91 conducted over 60-90 minutes. With the help of two moderators, the FGDs were conducted. All
92 the participants were comfortable with Nepali language, hence Nepali language was used for the
93 discussion. At first, information regarding sociodemographic factors was collected. All the
94 discussion was audio tape recorded for further translation and transcriptions. Two facilitators also
95 took field notes during the process and were discussed after the FGD. At first, information
96 regarding demographic factors were collected. Similarly, all the participants were encouraged to
97 share their knowledge, belief, and stigmata in society as experienced by them. To maintain
98 confidentiality and privacy of the participant's information, it was ensure none other than the
99 participants and the moderators attended the sessions.

100 **Participant selection**

101 The inclusion criteria were any cervical cancer survivors residing nearby BP Koirala Memorial
102 Cancer Hospital who have completed the treatment. The cervical cancer patients who have been
103 treated at BPKMCH were selected purposively and contacted via telephone. A total of 17
104 participants who agreed to participate in the research were invited to BPKMCH for further study.
105 BPKMCH is the only government cancer hospital with comprehensive cancer care, situated at
106 Chitwan district, Nepal. It provides health care to the overwhelming majority of the cancer patients
107 of Nepal.

108 **Data analysis**

109 The descriptive analysis of the socio-demographic characteristics of the survivors were done
110 (Table 1). Following data collections, audio recorded were translated and transcribed from the
111 Nepali language to the English language by two authors. Transcripts were examined line-by-line

112 and coded using themes as generated. The coding and thematic analysis were done using the
113 Microsoft Office Excel sheets. The two authors were involved in data analysis and reporting to
114 ensure the consistency of the data and the findings.

115 **Ethics approval and consent to participate**

116 The study protocol was approved by the Ethical Review Board of Nepal Health Research Council
117 (Reg. No. 152/2019). All participants were explained about the research objectives, their expected
118 role and the voluntary nature of participation. They were also informed that their decision to
119 participate or decline participation would not affect any benefits or services received by them. A
120 written informed consent (if literate) or thumb print in presence of witness (if illiterate) was
121 obtained before participation in the study.

122

123 **Results**

124 **Socio-demographic characteristics of the survivors**

125 The mean age of the participants was 53 years (SD 10.8). of age ranging from 35 to 81 years. On
126 average, the age of diagnosis of cervical cancer among the participants was 47 years (SD 8.7). In
127 our study group, 88% of participants were married whereas 12% were widowed. Majority (70.6%)
128 were Hindu by religion followed by Buddhism (23.5 %) and Christianity (5.9%). Most (64.7%) of
129 the participants were illiterate. A quarter of the participants had the history of cancer in their family
130 (Table 1).

131

132

133 **Table 1. Socio-demographic characteristics of participants.**

Variables	Frequency	Percentage
Age group (in years)		
35-50	7	41.2
51-65	9	52.9
66+	1	5.9
Marital status		
Married	15	88.2
Widowed	2	11.8
Religion		
Hindu	12	70.6
Buddhist	4	23.5
Christian	1	5.9
Level of education		
Illiterate	11	64.7
Primary	2	11.8
Secondary	4	23.5
Family history of Cancer		
Yes	4	23.5
No	13	76.5

134

135 **Awareness of survivors about cervical cancer**

136 In each group, survivors were asked about their idea of how they might have acquired cervical
137 cancer. All the survivors shared their knowledge about the cause of cervical cancer. The majority
138 of the women responded that they truly have no idea regarding the cause of cervical cancer (Table
139 2). Women described cancer as a painful experience they ever had. As one survivor stated,

140 *"... Look, I have no idea what is the cause behind my cervical cancer. It came out of nowhere. It*
141 *was such a devastating time when I discovered I had cervical cancer. I thought I was dying. All I*
142 *did was sit and ask myself why.... why it happened to me, did I do anything wrong?".... [60-year-*
143 *old (3)]*

144 While the majority remained clueless, few of them came along with some ideas of how they might
145 have acquired cervical cancer. The ideas about getting cervical cancer varied among individuals

146 and included fair skin color, short birth spacing, bearing too many children, unhealthy dietary
 147 habits, smoking and chewing tobacco, use of homemade menstrual cloths. One of the survivors
 148 even referred to the physical weakness in female as one of the causes of cervical cancer. When
 149 they were further asked specifically if they knew about the human papillomavirus (HPV), most of
 150 the survivors responded that they had never heard about the virus. Most of them did not know
 151 about the virus as the main causative agent of cervical cancer, while two of them came to know
 152 about the virus from their doctors after they discovered their cervical cancer.

153 **Table 2. Summary of survival reflection of the cause of cervical cancer.**

Survivor reflections of causes of cervical cancer	
<u>Theme</u>	<u>Representative quote</u>
Fair skin color	<i>"Well, I guess it is more common in fair women or you know like it may be due to short birth spacing. But exactly I don't know the cause of it [cervical cancer]." [46-year-old (16)]</i>
Short birth spacing	
Tobacco	<i>"I heard somewhere that smoking and chewing tobacco causes cancer. Well, I don't have those habits still I got the cervical cancer. I know that smoking and chewing tobacco causes cancer but, I wonder what caused cancer in me...."</i> [45-year-old (7)]
Unhealthy diet	<i>"I think that it [cervical cancer] is related to food. I mean to say that there must be something bad in the food we eat that predisposes us to cancer. Or you know, it may be due</i>
Bearing too many children	

Physically weak	<i>to bearing too many children. And also, women are physically weak which might be one of the reasons for us getting cancer." [62-year-old (15)]</i>
Use of homemade menstrual cloths	<i>"Growing up in a village, I did not have much knowledge about the health and sanitation. During my periods, I used homemade menstrual cloths. I guess I got cancer from those dirty pieces of cloths which I used during my periods. From my experience, I believe careless in menstrual hygiene causes cervical cancer." [59-year-old (4)]</i>

154

155 **Symptoms they experienced prior to diagnosis**

156 **Episodes of vaginal bleeding.** All the survivors were enquired about the symptoms
157 they experienced before they were diagnosed with cervical cancer. The majority of the women
158 reported that they had episodes of unexplained vaginal bleeding. One of them even attributed the
159 bleeding episode to hemorrhoids.

160 *"One day when I was in the bathroom, I saw blood in the pan, but falsely I attributed it to be from*
161 *the hemorrhoids. I was not aware what that could mean, but to be safe I went to see a doctor.*
162 *During my exam doctor told me that something isn't right and recommended me to undergo a*
163 *cervical biopsy. After a couple of days, I found out I had cervical cancer. He [doctor] suggested*
164 *me for the removal of my uterus which I was reluctant undergoing. Then I underwent an imaging*
165 *test [MRI], and thanks to God my cancer had not spread to my surrounding organs [urinary*
166 *bladder], and given the options I opted for the radiotherapy" [46-year-old (16)]*

167 **On and off abdominal pain.** One of the women reported that she had on and off
168 abdominal pain which she could not attribute to cervical cancer. She vividly recalled the event
169 when she was diagnosed with cancer as devastating news for her.

170 *"Initially, I used to have pain, on and off, in my lower belly and I took medicine from the nearby*
171 *pharmacy thinking it as a urinary tract infection. I don't remember for how long I had that*
172 *[abdominal pain]. Later, I was advised to see a doctor. During an appointment he [doctor] told*
173 *me my reports were concerning and after biopsy it turned out to be cervical cancer. The diagnosis*
174 *hit me very hard. I felt my world spinning around me when I knew I had cancer. I cried a lot. I had*
175 *no idea whether it is a genetic or something else."* [49-year-old (2)]

176 **Attributing vaginal bleeding to physiological changes.** Many times women attributed
177 their episodes of vaginal bleeding to the post-menopausal changes. Thinking bleeding as a
178 physiological change that can occur at any time after they have reached menopause, many women
179 did not seek immediate medical consultation.

180 *"At age 45, I had an episode of vaginal bleed and I discussed about it with my friends. They*
181 *believed that this [vaginal bleed] is pretty much common after you attain menopause and there is*
182 *no need for any medical consultation. But later, I had an episode of huge bleeding [from vagina]*
183 *and I was totally scared. Fearing there might be something wrong going on, I went for the medical*
184 *consultation right away. The doctor described me as I had some kind of wound in my cervix and*
185 *urged me to undergo cervical biopsy. Later, the report came as a cervical cancer and I got*
186 *operated and got my uterus removed."* [54-year-old (12)]

187 *"As far as I can remember, I did not bleed for long after I reached menopause. And suddenly out*
188 *of nowhere, I started having vaginal bleeding. I used to see blood even while passing urine. It was*

189 *a hot weather which I believed was the reason behind my bleeding. It did not improve for long*
190 *which made me worried. I went to meet the doctor. After all the examinations and tests like biopsy,*
191 *it came out to be a cervical cancer." [81-year-old (6)]*

192 **Acute severe vaginal bleeding.** In addition to the above symptoms in which women
193 did not seek immediate medical consultation, one of the women had heavy vaginal bleeding which
194 brought her to the emergent medical attention and through this, her cervical cancer was diagnosed.
195 *"I used to have lots of episodes of vaginal bleeding, which did not bother me initially. Later, I had*
196 *a heavy bleeding episode and even had clots in the bleed. It was like blood everywhere. Then*
197 *without thinking much, I decided to see a doctor. I was referred to a cancer specialist from local*
198 *hospital. They [doctors] told me to get cervical biopsy right away and asked me to see them in a*
199 *week. My son collected my reports later and opposite of what I expected the results came back as*
200 *positive for cancer. That moment is indescribable." [60-year-old (3)]*

201 **Barriers to Pap screening**

202 Women were enquired about their experiences with the Pap screening before getting diagnosed
203 with cervical cancer. Surprisingly, none of them ever had the screening with Pap smear before they
204 were diagnosed with cervical cancer. All of them avoided screening in the past because of
205 embarrassment or shame. As reported by them, women feel shy to expose their private parts to
206 doctors.

207 *"Well, I have to say most of the women feel too shy to go for screening and expose their private*
208 *parts to the medical professionals. Regarding me, I am not much comfortable with it, like, how*
209 *can I show my private parts to the people other than my husband." [61-year-old (13)]*

210 *"To be honest (smiling), women are not comfortable showing their private parts to others. Even*
211 *when we know about the medical camps in the nearby hospital or health post, we pretend to be*
212 *fine if we were asked by someone else and avoid going for the screening programs...."* [45-year-
213 old (7)]

214 Feeling healthy or having no symptoms at all was also mentioned to be one reason for women to
215 not go for screening.

216 *"I had a very bad experience. Back in time about 10 years ago, a cervical screening camp was*
217 *organized in our village. Without thinking much about it, I did not go there for screening, as I was*
218 *feeling well and believed nothing could be wrong going with me. But what I did was a mistake.*
219 *Later I got cancer and had to undergo surgery. If I had been careful enough and had undergone*
220 *the routine screening process, I could have avoided surgery and all the difficulties associated with*
221 *it. I am also a political leader in my ward so, I conducted a survey and you will be surprised*
222 *knowing that 72 out of 100 females did not have their routine screening done."* [59-year-old (4)]

223 **Cervical cancer in Nepalese society**

224 Women were enquired about how their family members and society treated them after knowing
225 that she had cervical cancer. The responses we got varied among individuals. Some of them were
226 well treated by their family and society, while others endured the stigma associated with cervical
227 cancer. The majority of the participants believed that even in present-day cervical cancer is
228 stigmatized in the Nepalese society because of the misconceptions people have towards cancer as
229 a whole (Table 3).

230 **Table 3. Summary of the stigma related to cervical cancer.**

Stigma related to cervical cancer		
<u>Drivers of stigma</u>	<u>Manifestation of stigma</u>	<u>Consequences of stigma</u>
Cancer as a death	Physical or social isolation	Loss of social support
Cancer is contagious	Verbal abuse	
	Self-stigma of fear	

231

232 **Drivers of stigma.** According to the women, the general themes acting as the driving
233 factors for cancer stigma in society are the people’s perception of cancer as an ultimate death result
234 and cancer as a communicable disease. Cancer as a whole is stereotyped as an ultimate death and
235 contagious in society and despite providing clear information by the affected person, most of the
236 time it was hard to change their views. It is due to the lack of clear information regarding cancer,
237 such beliefs do exist in society. As the respondents mentioned,

238 *“When the people in my neighborhood knew I had cervical cancer, they all [neighbors] believed*
239 *that it [cervical cancer] is a communicable disease and thought like you know, cancer is incurable,*
240 *I am not going to live for long.” [60-year-old (3)]*

241 *“The very first thing I used to hear from them [relatives] was “You are going to die soon from the*
242 *cancer”. In return I used to give them the information about my disease and say that this is curable*
243 *and I would be fine. But they did not believe me.” [47-year-old (7)]*

244 **Manifestation of stigma.** The fear that existed among the society members that it can
245 be transmitted via casual close contact and communication lead to the physical isolation or
246 marginalization of the cancer patients in their family as well as in the society. According to
247 respondents, neighbors started avoided coming close to them or inviting them in social events, and

248 even verbally abused and pitied them. Most of the time, they felt that they were hated by society
249 just because they had cancer. They mentioned how physical isolation and marginalization resulted
250 in the loss of their social support.

251 *"When I was undergoing chemotherapy for my cancer, my neighbors stopped coming near to me*
252 *thinking that they would get cancer from me. Even my family members wore mask when they had*
253 *to come near me."* [60-year-old (3)]

254 *"Back in our time, people from our village used to take cancer in a very negative way. When I got*
255 *cancer, they [villagers] didn't even allow me to go near them and used to say "go away" if I*
256 *attempted to do so."* [81-year-old (6)]

257 *"I had a very hard time dealing with my diagnosis of cervical cancer. That was the first time*
258 *anyone outside my family came to see me and pitied me. During my chemotherapy, I lost my hair*
259 *and my neighbors believed it was happening due to my cancer. I don't know why but they*
260 *[neighbors] always gave me disgusting look when I said I am undergoing radiotherapy. I felt like*
261 *everyone hated me."* [47-year-old (7)]

262 **Self-stigma of fear associated with cancer.** The fear related to cancer and its
263 treatment also existed in those living with cancer. Due to the negative connotations of cancer,
264 women having cancer often feared to undergo the treatment. As one of the respondents mentioned,
265 *"Initially I was reluctant to undergo the treatment of my cancer [cervical cancer], as one my friend*
266 *told me not to go for treatment as the cancer will eventually kill me and also the radiotherapy is*
267 *very difficult to undergo. Later I met a woman with cervical cancer who encouraged me to undergo*
268 *treatment. After hearing her experience my perspective towards chemotherapy and radiotherapy*
269 *changed. Meeting her eased my fears. I am grateful that I met her, otherwise I would not have*

270 *gone for the treatment and only God would know what would have happened to me...hahaha....."*

271 [40-year-old (10)]

272 **Social support and family encouragement.** According to them, the love, care, and
273 support they got from their family and friends were the key elements for them to fight cancer and
274 stay optimistic through the journey of cancer.

275 *"I had a very good support from my friends and family (smiling). They treated me very well when*
276 *I got cancer and was undergoing treatment. I am so glad that they were all so supportive and with*
277 *me when I needed them the most."* [46-year-old (16)]

278 *"My family looked after me very nicely. I can't say enough about them who cared for me during*
279 *my hard time. Now, I love them more than ever. They are the most important person in my life."*
280 [45-year-old (1)]

281 *"Yes, family support played a great role in my survival. I do not have enough words to express my*
282 *gratitude for the care, help and love I got from them. They were always by my side I needed them."*
283 [59-year-old (4)]

284 According to a few respondents, society's perception overturned with time as they saw the patients
285 with cervical cancer doing well with the treatment and also with the increasing awareness via
286 media. As one of the survivors stated,

287 *"At present, the situation is quite different than the previous one. With the awareness arising from*
288 *the media and campaigns, their perspective towards cancer changed. Now they [society] feel*
289 *ashamed of how they previously treated cancer patients. These day people are very supportive*
290 *towards the cancer patients....."* [81-year-old (6)]

291 **Unexpected misconceptions**

292 A few uncommon views regarding the cancer were identified from our interview. People have few
293 misconceptions regarding the type of food they should take and the use of herbal medicine. They
294 avoided a certain type of food during their period of cancer. One of the survivors avoided meat
295 and eggs, while one patient consumed only pulses, milk, and fruits. Among them, one took some
296 herbal medicines recommended by her friend, which she does not know about.

297 *"I did not like to eat for a month. I just eat pulses, soups, milk and fruits only during my treatment.*
298 *Sometimes I used to panic a lot and pray to god for my survival. I believe I would not survive if*
299 *God was not there....."* [60-year-old (3)]

300 *"I did not eat meat for 1 year and also the eggs....."* [61-year-old (13)]

301 *"One of my neighbors was diagnosed with some serious disease, I don't know exactly what it was,*
302 *but I know is she was doing fine by taking some herbal medicines. She named about 13 types of*
303 *herbal medicines she was taking. Seeing her I also started taking those [herbal meds] on daily*
304 *basis. I believe that also gave great benefits to my health."* [53-year-old (11)]

305 **Message of the survivors**

306 The majority of the women did not go for the Pap screening for cervical cancer, and also after
307 being diagnosed few of them were reluctant to undergo treatment. However, though lately, but
308 with their own experiences with cancer, they realized the importance of screening methods for
309 early detection and treatment of cervical cancer.

310 *"I heard about one cancer patient who did not undergo radiation therapy because of all the*
311 *negative comments she heard about radiotherapy, its complications. I don't know where she is*

312 *now. That is certainly a mistake. Please don't do that, please go and get your treatment before it*
313 *is a delay so that you don't have to regret it forever."* [51-year-old (8)]

314 *"Today I am living a new life. For those women out there who are healthy, I suggest them to go*
315 *for screening regularly. And to those living with cervical cancer, don't worry much about it. Yes,*
316 *cancer is a disease but is not always a killer; they can be cured with treatment."* [60-year-old (3)]

317 Thus, they advised other healthy women to undergo regular screening for early detection and
318 undergo treatment if they are diagnosed case of cervical cancer.

319

320 **Discussion**

321 This qualitative study done to explore the experiences of cervical cancer survivors is the first of
322 its type that had been conducted in Nepal. Survivors expressed their perspectives of cervical cancer
323 and its cause, symptoms they had a prior diagnosis, their cervical cancer screening behavior,
324 personal and social consequences they had faced after the diagnosis. The majority of the
325 participants had scant information about cervical cancer. They delivered various ideas of how they
326 might have acquired cervical cancer, and when specifically inquired about the human
327 papillomavirus they responded that they had never heard about the virus before and can't relate the
328 virus to the development of cervical cancer. The majority of participants had not undergone the
329 regular Pap screening before diagnosis, and many had not screened at all. The main barrier to
330 screening as reported was the fear of embarrassment that results from showing their private parts
331 to the medical professionals and having no symptoms at all. The majority of survivors had
332 persistent symptoms before they got diagnosed with cervical cancer. Despite having symptoms for

333 long, they shockingly showed delayed healthcare-seeking behavior. Although all survivors did not
334 face the stigma related to cervical cancer, the majority of them endured the stigma for long in the
335 form of physical or social isolation and verbal abuse. Though lately but eventually the survivors
336 recognized the importance of the early Pap screening and treatment of cancer. Thus, many
337 survivors urged other healthy women to get screened regularly and go for the treatment if they
338 already had it.

339 Several findings can be derived from the study. First, the women we did an interview with had
340 scant information about cervical cancer. While few of them related their cancer to some of the
341 factors, the majority of them had no idea what the cause of cervical cancer in them is. Almost all
342 of them never heard about human papillomavirus (HPV) before and had no clue that it can cause
343 cervical cancer. Among the participants, 64.7% of the women are illiterate and illiteracy is perhaps
344 the reason behind their lack of knowledge about cervical cancer. Several other studies in Nepal
345 reported a lower level of knowledge in women about cervical cancer. For example, in a study in
346 Rukum, Nepal only 5% of the 600 participants had ever heard about cervical cancer and only 30%
347 among themselves were able to relate HPV as its causative agent [6]; in a study in Eastern Nepal,
348 only 21.5% of women could identify HPV as a causative agent of cervical cancer [7], and in
349 another study in rural Nepal 76.24% (1928) of women did not know anything about cervical cancer
350 [8]. A similar finding was present in a study among cervical cancer survivors in North Carolina,
351 USA [9]. The study in Rukum, Nepal articulated a lower level of knowledge about cervical cancer
352 in women to their low level of education and lower monthly income [6]. This highlights the
353 importance of implementing educational programs and campaigns to educate women and make
354 them aware of cervical cancer.

355 Second, the barriers to cervical cancer screening identified from the study are feeling well or
356 having no symptoms at all and the fear of embarrassment that results from showing their private
357 parts to the health professionals. In addition to this, other studies in Nepal identified illiteracy
358 [6,10,11], lack of awareness about cervical cancer and its screening methods, embarrassment,
359 having no symptoms at all [12,13], fear of finding out cancer [8], sociocultural barriers, service
360 providers' behavior, geographical challenges, poor financial condition [13] as a significant barrier
361 to cervical cancer screening uptake behavior, while living in a rural area [11], participating in
362 awareness program, support from family and women's group [13] act as a facilitator to increase
363 the screening uptake in women. Similarly, a cross-sectional study in Morocco also reported poor
364 awareness in women about cervical cancer and have no symptoms at all as a cause for poor Pap
365 screening uptake practice [14]. Moreover, stigma related to cervical cancer was identified as a
366 barrier to cervical cancer screening in Karnataka, India [15], and poor finances and lack of
367 insurance, sense of well-being, transportation issues and dissatisfaction with the behavior of
368 service provider were some issues related to poor screening behavior among survivors in North
369 Carolina, USA [9]. Prior bad experiences with the detection of cancer were also described as a
370 barrier to cervical cancer screening among older African American and Hispanic urban women
371 [16].

372 The findings suggested the need for interventions at multiple levels to increase the screening
373 uptake behavior in women. First, women should be educated and made aware of the importance
374 of screening, whether they have symptoms or not, and how early detection and treatment can
375 significantly prevent cervical cancer. Second, there seems a need for organized cervical cancer
376 screening programs in Nepal to make it accessible to women in all the geographical areas and
377 cheap enough to make them affordable. Awareness programs via media, mass campaigns,

378 healthcare professionals all can equally increase the screening uptake behavior in women. As been
379 reported in the literature, educating women about the importance of screening had shown an
380 increase in the willingness to participate in such programs [17,18]. Using the newer information
381 technologies, like using the reminders and messages via the cellphones [19] or involving the social
382 media influencers or key opinion leaders [20] for increasing awareness have shown to increase the
383 participation of women in cervical cancer screening. A similar use of the latest technology in social
384 media can be implemented in Nepal for increasing the awareness.

385 Third, the majority of women experienced episodes of unexplained vaginal bleeding which
386 persisted for long before the diagnosis. Though they had easy access to health care (being residents
387 of urban areas), the majority demonstrated delayed healthcare-seeking behavior. As this study
388 indicates, the women's sense of well-being and inability to relate their symptoms to a possible
389 serious disease or attributing their symptoms to normal physiological changes like menopause
390 possibly explain their delayed healthcare-seeking behavior. Similarly, delayed healthcare-seeking
391 behavior despite persistent symptoms was also noted in cervical cancer survivors in North Carolina
392 [9]. On the other hand, some studies articulated the delayed healthcare seeking to the stigma related
393 to cervical cancer [15]. This behavior seems concerning as this frequently leads to delayed
394 presentation to medical attention thus, leading to delayed diagnosis and treatment which can
395 increase the negative impact of disease in affected individuals. The women should be educated
396 about the fact that the sense of well-being does not ensure everything is going alright in them and
397 should never be used to rule out the need for routine screening measures or medical consultation.
398 Women should be educated about the symptoms related to cancer, encouraged to seek medical
399 care when they become aware of any symptoms related to cancer. Likewise, effective

400 communication seems important between the health-care providers, policymakers, and the public
401 via educational programs, media to improve the knowledge about cancer in women.

402 Fourth, even in today's modern era, cervical cancer is still being stigmatized and misunderstood
403 in our society. It is quite surprising that despite being such a highly prevalent disease, the public
404 has scant information, misunderstood, and has different perspectives about cervical cancer. The
405 misconceptions regarding cervical cancer seem to originate and keep perpetuating the stigma
406 related to it. Our study revealed that pertaining cervical cancer to ultimate death and fear of
407 transmission assuming it as a communicable disease are the driving factors for the origin of stigma.
408 Similar perceptions, cancer as a communicable disease and leads to ultimate death, driving the
409 stigmas related to cervical cancer are also described on a qualitative study of stigma related to
410 cervical and breast cancer in Karnataka, India [15] and a study on stigma related to cervical cancer
411 among women in Brazil [21]. Furthermore, the mind of the people being so constantly preoccupied
412 with the thoughts and ideas of blaming or attributing cervical cancer to the individual's
413 promiscuous sexual behavior, like sleeping with multiple men, or relating it to sexually transmitted
414 disease [21] or blaming cervical cancer as a punishment to individual's bad deeds/transgressions,
415 like assuming they must have done something wrong [15], it naturally rooted the stigma related to
416 cervical cancer. Blaming cervical cancer to the promiscuous sexual behavior was also described
417 as a driving factor in a qualitative study to identify the social stigma among cervical cancer
418 survivors in American society [22] and an experimental study to explore the knowledge of HPV
419 link to cervical cancer and stigma in Florida, America [23]. A study in Zambia also found that
420 women perceived cervical cancer as an ultimate death and blamed cervical cancer to the
421 promiscuous sexual behavior [24].

422 The stigmas associated with cancer manifested in various forms in the communities and women
423 had to endure the discrimination and negative impacts arising because of it. Although all the
424 women were not the victim of stigma, majority of the interviewees described the enacted stigma
425 as discrimination in the form of social isolation or marginalization ranging from no longer coming
426 in close contact to the person with cancer, inviting them to participate in social events to use of
427 masks from the family members while coming in contact to them. Verbal stigma was also
428 described as offensive remarks towards cancer patients like “do not try coming near to me, go
429 away”, “you are going to die soon from cancer”. Other studies have also described similar
430 manifestations of stigmatization. The physical or social isolation and verbal abusive comments
431 had also been described in a study in Karnataka, India [15], and in a study on cervical cancer
432 stigma in rural Kenya [25].

433 Unsurprisingly, the stigmatization has negative impacts on cancer patients on both personal and
434 social levels. Interviewees reported how the marginalization of them from society led to the loss
435 of their social support. A study in Karnataka, India described how the diagnosis of cervical cancer
436 generated a fear inside a cancer patient and their kin whether to disclose their diagnosis to others
437 or not and how they held revelation of the diagnosis within their close family members only. The
438 stigmas related to cervical cancer was a potential barrier to screening and led to delayed healthcare-
439 seeking behavior among women having symptoms [15]. As described in a study done in America
440 women felt guilt, embarrassment, and shame as a result of their cervical cancer diagnosis, and
441 generated a fear inside them about being misjudged by the society upon disclosure of diagnosis,
442 and how it led to the loss of social support [22]. A study in Canada described the discriminative
443 behaviors towards cancer (of any type) survivors in their workplace like discrimination while
444 hiring, harassment, bullying, demotivating them to quit their job, or retire early [26]. Though

445 workplace discrimination is not explored in this study, cervical cancer survivors may face the same
446 consequences in their workplace.

447 The study adds to the body of research seeking a broader understanding of stigma and its impact
448 on women's personal and social life. As reported by few respondents that with time when the
449 cervical cancer patient got better with treatment, it overturned the thoughts and beliefs of most
450 people towards the stigma related to it. Thus, it shows the importance and needs to implement the
451 awareness programs at an individual and community level to change the way cancer is stereotyped
452 in society.

453 Lastly, the survivors, though lately, but realized the importance of regular screening in early
454 detection and treatment of cancer, and changed their perspective towards cancer. Almost all
455 survivors urged other women to seek medical care when they had any concerning symptoms.
456 Cancer is a devastating diagnosis to face and digest and can scare anyone. Forming a group of
457 survivors and providing an opportunity for cancer patients to interact with them can ease resolve
458 the fear of cancer and encourage them to opt for the treatment.

459 **Study strength and limitation**

460 **Strength.** This is the first study conducted in Nepal in an attempt to explore the experiences
461 and perspectives of cervical cancer survivors. The qualitative study design itself is the strength of
462 this study. By using this qualitative approach, we were able to assemble the comprehensive
463 understandings of the survivor's perspective of cervical cancer and their journey through this
464 cancer. The conclusion drawn from this study can add a vital element in this research area which
465 can help improve and modify accordingly the awareness campaigns and health care policies, that
466 will implement soon.

467 **Limitation.** The study findings cannot be generalized as the chosen sample for the study is
468 purposive and from Chitwan district only and does not reflect the entire female population of
469 Nepal. The knowledge, experiences, and stigma women endured through in the urban settings may
470 be different compared to those experienced by women in the rural setting. We interviewed only
471 those who are alive and volunteered to share their story with us. It would add much more flavor in
472 our study if we add the perspectives of the community and women living with cervical cancer.

473

474 **Conclusions**

475 This study demonstrated poor awareness about cervical cancer, delayed healthcare-seeking
476 behavior, and the stigma related to cervical cancer. Thus, there is an urgent need of intervening at
477 multiple levels, at the community level to make women and the public aware of cervical cancer to
478 the federal level for launching effective health education campaigns and making policies for
479 cervical cancer prevention programs. Additionally, the survivors should be included as an integral
480 part of the health policy formation. The implementation of such programs may save the lives of
481 hundreds of women and overturn people's perspective towards cervical cancer thus, saving women
482 from going through all the negative experiences related to cervical cancer. This study also
483 recommends more qualitative studies with the cervical cancer survivors in both urban and rural
484 settings to gain their perspectives, knowledge, experiences, and attitudes about it and add them to
485 our research.

486

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