

1 Dignity Enhanced through Faith & Family Support in Palliative Care: A 2 Qualitative Study

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10 Abstract

11 **Background:** Dignity is integral to palliative care. Illness can diminish it, causing hopelessness and the
12 wish to hasten death. Yet, dignity is a complex multidimensional phenomenon, influenced by values and
13 context. Understanding its varying interpretations can inform practice and policy. The aim of the study is
14 to explore the understanding of dignity in adult patients with palliative care needs from a Lebanese
15 perspective and how it is preserved during illness and while receiving health services.

16 **Design:** Qualitative interview study underpinned with a social constructionist lens. Fourteen patients
17 recruited from home-based hospice and outpatient clinics in Lebanon. Data analysed using reflexive
18 thematic analysis.

19 **Results:** Four themes were developed across all the interviews: a) Dignity anchored through faith in God
20 and religious practices; b) Family support in maintaining physical, psychological wellbeing, and social
21 connectedness; c) Physical fitness, mental acuity, and healthy appearance through which patients may
22 escape the stigma of disease, d) accessible, equitable, and compassionate healthcare.

23 **Discussion:** Dignity is elusive and difficult to define but faith and religious beliefs play a significant
24 contribution in this study. For the participants, illness is seen as a natural part of life that does not
25 necessarily diminish dignity, but it is the illness related changes that potentially affect dignity. Findings
26 show the importance of family and children in preserving dignity during illness and how their active
27 presence provide a sense of pride and identity. Participants aspired to restore physical, social, and
28 mental well-being to reclaim their dignity and normalize their lives. Challenges related to physical
29 appearance, memory loss, vitality, and social stigma associated with illness diminished dignity.
30 Accessible, equitable and compassionate healthcare services are also crucial in preserving dignity.
31 Participants valued clear communication, respect, and empathy from healthcare providers and identified
32 affordability of care essential for maintaining dignity.

33 **Conclusion:** Faith in God, and strong family ties are dominant elements to maintaining dignity in the
34 Lebanese context. Relational connectedness with family, children or God is also a need in maintaining
35 dignity in other communal countries with variations in emphasis. The study indicates that religious and
36 cultural context shapes the needs and perceptions of dignity during illness. These findings are likely to be
37 transferable to many Middle Eastern countries but also countries with strong religious and family ties
38 globally.

39 **Key words:** dignity, palliative care, qualitative research, faith, family, Middle East

40 Introduction

41 Dignity is an integral principal in palliative care (1). Patients with advanced chronic or terminal
42 illnesses with palliative needs may experience heightened functional dependency, limited
43 control, and loss of hope, that may negatively impact self-image, leading to isolation and poor
44 quality of life (2-4). The heavy burden of disease and increased vulnerability may even lead to a
45 loss of dignity and a diminished desire to live in some individuals (1, 5). Thus, preserving dignity,
46 defined as “the quality or state of being worthy, honoured, or esteemed” or the personal
47 perception of being respected by others and maintaining a good self-esteem (6), is crucial to
48 enhance quality of life in palliative care (4).

49 Some patients have identified loss of personal privacy, (7) physical and economic dependency
50 (8) as threatening to dignity during illness. Health care providers’ attitudes and discourse while
51 providing care, such as an authoritarian or curt communication, being omitted from decision
52 making processes and lack of empathy can adversely impact a patient’s dignity (7-9) . On the
53 other hand, respecting personal stories and patient autonomy has been found to uphold patient
54 dignity (10).

55 The concept of patient dignity, measurements of dignity related distress, and dignity promoting
56 interventions in palliative care have been well debated in the global north and some Asian
57 countries showing variations in dignity interpretations (11-18). However, dignity remains
58 minimally assessed in the rest of the world including the Middle Eastern setting. Scarcity of
59 knowledge from the Middle East leaves the utility of the existing research on dignity and its
60 translation uncertain.

61 This paper aims to explore the understanding of dignity in adult patients with palliative care
62 needs from a Lebanese perspective. Lebanon has endured a history of political and economic
63 turmoil associated with sectarianism and an influx of refugees from neighboring countries (19).
64 People still die in uncomfortable and distressing situations often without access to palliation
65 (20-22). Lebanon is categorised as a group 3a country on the palliative care development scale
66 where service delivery is isolated, heavily dependent on donors, with minimal availability of
67 morphine(23). As palliative care values permeate in countries like Lebanon, a deeper
68 understanding of the key tenets of palliative care, such as dignity, is imperative to foster
69 informed practices that enhance it. To provide culturally relevant care, it is important to ask
70 what is the understanding of dignity for patients with palliative care needs from the viewpoint
71 of the Lebanese?

72 To achieve the aim of this study, the following objectives were pursued:

73 A. Explore the understanding of the concept of dignity in patients with palliative needs as
74 perceived by patients.

75 B. Examine how dignity is experienced while receiving health services in adult patients with
76 palliative needs.

77 **Methods**

78 **Study Design**

79 A qualitative study with patients experiencing advanced chronic illnesses or terminal conditions.

80 Social constructionist theoretical lens underpinned the study. As such, knowledge is *interpreted*

81 *and co-constructed* between the participants and the researcher and conceptualized in the
82 prevailing socio-political and economic framework (24-27). Reflexive thematic analysis was used
83 (28, 29).The consolidated criteria for reporting qualitative studies (COREQ) guidelines was used
84 to report the findings (30).

85 **Setting**

86 The study took place in Beirut, Lebanon, where most large health care services are located. The
87 setting was a home-based hospice service and an outpatient clinic for people with chronic
88 healthcare conditions of a large tertiary private hospital. Both institutions serve patients from
89 various socioeconomic and geographical backgrounds.

90 **Population**

91 The participant inclusion criteria were the following:

- 92 a) Adults of aged 18 years or more, since dignity conditions may vary with children (28).
- 93 b) Living with advanced chronic or terminal conditions in need of palliative care such as solid or
94 blood cancer, organ failures (heart, kidney, liver, lung disease), progressive neurologic/
95 autoimmune disorders (Parkinson's, Crohn's disease, Systemic Lupus Erythematosus), or other.
- 96 c) Participants admitted to the hospital at least once in the past year, to ensure recent exposure
97 to health care services.
- 98 d) Participants who are cognitively intact, willing to be interviewed, capable of conversing in
99 Arabic, English or Armenian and granting consent.

100 Those participants who were too ill or too distressed such as complaining of pain,
101 breathlessness or other symptom that destabilizes their condition as identified by their
102 physician or nurse were excluded. Participants who did not need palliative care, or had
103 cognitive impairment were excluded, too.

104

105 **Sampling**

106 Purposeful sampling of participants was implemented from whoever was accessible due to the
107 restrictions imposed by Covid-19(32).

108 **Recruitment**

109 The physicians in the outpatient clinic and the nurses in the home-based hospice service,
110 identified potential participants and facilitated access to the researcher (SDS) to contact them
111 and provide details of the study. The researcher did not have any relationship with the
112 participants. When recruitment became challenging due to the Covid-19 pandemic, additional
113 participants were identified through snowballing, where a participant was identified through a
114 previous participant. Time was allowed for questions or expressing concerns before consenting
115 and data collection. The researcher SDS resides in Lebanon and has a background of nursing
116 education and is currently a nursing instructor with good interviewing skills. The researchers
117 (YS) and (NP) are experienced researchers in palliative care and were supervising the overall
118 research process.

119 Data Collection

120 Written consent was obtained for the in-person interviews and verbally recorded for the
121 telephone interviews. All participants who were approached accepted enrolment. Participants
122 were asked about their understanding and experiences of dignity during their illness and while
123 utilizing health care services. A topic guide, based on the findings of other empirical studies,
124 (supplementary document), was designed to ensure the research question was covered (33,
125 34). 'What does dignity mean to you', 'How does it change during illness?', 'What actions
126 enhance or diminish dignity while receiving health services?' were some of the questions asked.
127 Participants were encouraged to elaborate or clarify their responses when needed (35, 36). As
128 the researcher (SDS) was multilingual, the interviews were conducted in English, Arabic or
129 Armenian at the participants' request. Demographic information was collected before the
130 interview (presented in Table 1). With the participants' permission, interviews were audio
131 recorded, and transcribed verbatim. Field notes about the setting, the patient's mood, and
132 overall tone were kept by the researcher after the completion of the interviews and included in
133 the data analysis. Data collection stopped once information sufficiency had been achieved (37,
134 38).

135 Data Analysis

136 All interviews were translated into English. Some terminologies in Arabic or Armenian that did
137 not have an accurate translation were kept in their original language in the transcripts to
138 preserve their contextual meaning(39, 40). The interviews were analysed using reflexive
139 thematic analysis (41) following the six steps identified by Braun, Clarke (42): a) familiarizing
140 with the data, b) generating initial codes, c) searching for themes, d) reviewing the themes, e)

141 defining and naming the themes, and f) producing the report (43). The researcher remained
142 loyal to the words used by the interviewees. The themes were developed inductively from the
143 codes that appeared as patterns across the data. Analysis was conducted at the semantic
144 explicit level as well as examining implicit meanings, concepts, assumptions and social
145 implications (43). For example, when a participant expressed concern that he is not able to take
146 long walks or flirt with women, or when another one described feeling shameful when wearing
147 a wig, these findings allowed the researcher to revisit the social concept of self-image and how
148 it implicitly influences perceptions of dignity and self-worth. The process was reflexive and
149 recursive requiring frequent revisions and refinements (41, 44-46). NVivo qualitative data
150 analysis software version 11 was used to manage the data, visualize connections to assist
151 interpretation (47).

152 The credibility of the analysis was maintained through the researcher's internal examination
153 and awareness of personal biases and social positioning as a female nursing instructor that
154 could have affected the findings. A reflexive diary was kept ensuring transparency throughout
155 the phases of the research (42, 46). Pseudonyms were applied to protect the identity of the
156 participants.

157 As the research was conducted in Lebanon, and was part of a PhD thesis project, research ethics
158 committee approval was secured from the American University of Beirut Institutional Review
159 Board (IRB- ID: SBS 2020-0033) and from the Lancaster University Faculty of Health & Medicine
160 Research Ethics Committee (FHMREC19139). Since the topic was sensitive A distress protocol
161 was in place and the interviewees were offered to pause whenever needed to take time, reflect
162 and then resume to avoid emotional distress or stop the interview if required (48).

163 Findings

164 Fourteen patients were included in the study. All potential participants agreed to participate in
165 the project. Four interviews were conducted in person in their homes (in line with Covid-19
166 guidelines) as per participants' wishes, and the rest by telephone between September 2020 and
167 April 2021. The interviews lasted between 5 minutes (this participant rapidly became too tired)
168 to 79 minutes with a median of 38 minutes. Four themes and 15 sub-themes were developed in
169 response to the research question (see table 3). Each theme is described as to how it enhances
170 dignity during advanced chronic and terminal illness in palliative care patients with illustrated
171 quotes.

172 **Table 1. Participant Demographics**

Gender	Number of Participants
Male	5
Female	9
Religion	
Christian	10
Muslim	4
Marital Status	
Married	11
Single	2
Widowed	1
Age	
45–54	3
55–64	1
65–74	6
75–84	3
85–94	1
Diagnosis	
Cancer	6
Organ Failure (<i>chronic obstructive lung disease; heart failure, kidney failure</i>)	6
Neurological disorders	2

174 **Table 2. Themes and Supporting Subthemes**

<p>‘I have my faith you know... whatever will happen will happen.’</p>	<ol style="list-style-type: none"> 1. Dignity is a loose and abstract concept. 2. Dignity is inherent and not affected by illness. 3. Illness is accepted as a regular life event in older participants. 4. Dignity in illness is enhanced through faith.
<p>‘Thank God I have my Children.’</p>	<ol style="list-style-type: none"> 1. Bearing children reinforces dignity. 2. Patients rely on children and spouses for support and personal care during illness. 3. Family highly involved in patient health care. 4. Visitors and staying connected boost dignity during illness.
<p>‘I changed upside down...’</p>	<ol style="list-style-type: none"> 1. Maintaining energy to carry on with regular physical and social activities. 2. Preserving memory and cognitive ability. 3. Maintaining outer appearance, image, and social reputation. 4. Illness is stigmatized; hence, patient is eager to finding cure to preserve dignity.
<p>‘The physician kissed me on the forehead and told me nothing is wrong with me.’</p>	<ol style="list-style-type: none"> 1. Compassionate care and presence of health care providers restores dignity. 2. Clear and non-judgmental communication from health care providers. 3. Accessible, affordable, and quality services and medicine for all patients regardless of social or economic rank.

175

176

177 **Theme One: Dignity anchored through faith in God and religious practices.**

178 **‘I have my faith you know... whatever will happen will happen.’**

179

180 In this theme the fluidity in understanding the nature of dignity was explored and how it is enhanced

181 through faith, religious beliefs, and morality as viewed by the participants who came from a range of

182 religions. Whenever patients were questioned about their perceptions of dignity, many did not

183 comprehend the question and so the interviewer gave examples of life situations that may be dignifying
184 such as weddings. Participant's understanding or description of the concept of dignity was blurry
185 regardless of gender, language, or ethnic group. Participants said that the word was loose and difficult to
186 encapsulate. Others explained that dignity is something felt *within* the self, associated with emotions.

187 - *'I don't know "ezet nafs" (self-esteem) and dignity are so vague and can't be defined and limited.*
188 *It represents your inner being and world.... I do not know.... If you want, ask me more specific*
189 *topics and I can answer.'* Patient # 5

190
191 The concept of dignity was not necessarily related to health status, instead it was an inherently
192 preserved human feature. Illness was regarded as a natural occurrence in life, something that anyone
193 may experience without damaging their dignity or worth. Some participants believed that illness is
194 predetermined from the creator, and that the almighty God is in control of everything, the source of
195 offerings as well as losses.

196 - *'No, no for me dignity is not affected by illness, they are not in the same boat.... Dignity for me*
197 *has a different stance, different understanding. Illness is completely something else, why should it*
198 *affect/ damage my dignity?'* Patient # 1

199
200 Participants stated that dignity during illness is enhanced through faith and loyalty to the Almighty and
201 religious practices. It is cultivated through demonstrating devotion to the religious virtues and values
202 inscribed in sacred scripts of their religion, *'do not harm people, be good, do not gossip'* Zein,
203 establishing a closer connection between the individual and divinity. Participants expressed consolation
204 and a safe refuge for their dignity through their faith in God who 'listens to the sufferers'. Through
205 prayer, watching religious television programs, reciting verses, and participating in WhatsApp spiritual
206 group communities, participants evoked a sense of hope and wellbeing fostering their dignity.

207 - *'It was not a personal or lonely struggle with the medical condition, but I felt that someone, the*
208 *Lord, was with me... and the dignity I received from my faith made me feel that someone is with*

209 *me, I am not alone... there are things that cannot be fully expressed in words... you just feel*
210 *them, you feel the presence of the Lord with us.' Patient # 9*

211

212 Theme Two: Family support in maintaining physical, psychological wellbeing, and social
213 connectedness 'Thank God I have my Children.'

214

215 Participants explained that family members, children, and their social relationships are the
216 building blocks and fundamental mesh where dignity is safeguarded during illness. The
217 interviews reveal that living in or establishing a family and bearing children are core societal
218 values that reinforce individual dignity, identity, and wellbeing. According to participants, being
219 surrounded by family members and children is considered a loving shield, protective against
220 physical, psychological, or economic threats to dignity. The family's presence around the patient
221 during hospitalisation is perceived as of utmost necessity as it feeds into the person's identity,
222 social status, worth, and dignity.

223 - *'Dignity will change when the person does not have a family to dignify him/her and take care of*
224 *him ..., this is when dignity changes. However, thank God, I have my children, they work, and*
225 *they are employees, so they preserve my dignity. Thank God' Rima Patient # 3*

226

227 Children are regarded as the legacy of the participants to whom they pass on their values,
228 'wisdom', and personal stories, finding fulfillment and continuity that enhances dignity.

229 - *'My wife and children are very good [hamdellah], and I live with them. My wife is also very good,*
230 *she takes care of me ... My children are with me, my wife is near me, and I own a house (an*
231 *apartment) and the children do for me whatever I need, you understand?' Patient # 4*

232 Married participants take pride in their children and those with no children celebrate their own
233 personal successes, their achievements, and involvement in the community as their archive of
234 personal dignity.

235 - 'yes, I forget everything, but they (my children) are above all, they are the most important thing
236 for me, especially that I have my condition, for me, my family is the most important thing' Patient
237 # 1

238 A loving husband or a wife, who assists in the daily needs, and is loyal and empathetic towards
239 them is a major source of support to boost dignity 'the love that I enjoyed surrounding me was
240 amazing ...' Nelly. In contrast, a husband, or a wife who is distant, uncaring, or not involved in
241 the care reduces dignity and is even a source of distress.

242 - 'even my husband didn't take care of me, neglected me "[ma tallae feyye]" (he never laid eyes
243 on me), I was trying to support my back and my lungs were hurting as if I am holding one ton of
244 heaviness on my spine, and at the same time, I have to do my house chores, I needed to go up
245 and wash the dishes and my tears filled my eye [dmooeei aala aaynayye], ...So, I did not find
246 any help from my husband ' Patient # 7

247

248 Having visitors at times of illness and receiving calls is a sign that the individual is respected and
249 missed in the social circle. Family members or friends living abroad come over to visit and
250 support the ill person. This is a cultural norm that bears the meaning of reciprocity in caring,
251 courtesy, and respect to the sick.

252 - 'it's not only that my brothers came over from Europe to visit me, I tell you all the whole
253 neighbourhood came over for a visit. All the neighbourhood was here. If they don't respect or
254 care for me and I don't respect them, do you think they would have come to see me?' Patient #
255 2

256

257 Theme Three: Physical fitness, mental acuity, and maintaining healthy appearance
258 through which patients may escape the stigma of disease 'I changed upside down...'
259

260 Participants aspired towards restoring their physical fitness, mental and social wellbeing, vitality,
261 and normal life. They hoped to escape from illness and its attached stigma, to reinstate
262 normalcy, and restore dignity. Preserving physical energy, functionality, and appearance, were

263 one of the defining elements of dignity in illness. The ability to move around, take care of
264 personal needs independently (toileting, bathing, eating), be symptom free, pursue a career, go
265 to outings for relaxation were other core elements of feeling dignified.

266 - *'The things that changed in me are ... what can I say...I changed upside down. I was a*
267 *gentleman, I loved going to trips, to have fun, I love enjoyment and partymy condition is not*
268 *the same now it turned upside down. This is the truth...I used to walk from here (cheifat area) to*
269 *Beirut governmental hospital and come back on my feet. It's not the same now.'* Patient # 2

270

271 Memory loss or mental confusion is mentioned as a barrier to maintaining dignity as it takes
272 away not only the ability to make decisions, but also the capacity to start a meaningful
273 conversation or socialise with others. As expressed by one of the participants, without her
274 memory she was *'living in a trance or void'* Mary, she was invisible like having lost her identity.

275 The outer appearance of the participant, such as maintaining intact skin, preserving the whole
276 body without losing a body part, for example a breast, enhanced dignity. Clean clothes, healthy
277 hair, teeth, were fundamental to self-esteem that boosted dignity particularly for women.

278 Wearing a wig due to chemotherapy-induced alopecia was one of the most frustrating
279 consequences of the treatment. Women tended to feel embarrassed, unable to discuss hair loss
280 openly, coping with it through concealment and by wearing additional make-up.

281 - *'Hmmm... I will tell you that for me the worst thing was my hair loss and the use of a wig. This*
282 *was a topic that was very difficult for me to accept. Even when things were well, and I resumed*
283 *going to work (as a teacher at school) that topic I couldn't talk about ... I was really touched by*
284 *it and ashamed of'* Patient # 10

285

286 On the other hand, men were mostly annoyed by their lack of physical fitness, fatigue, and
287 limited energy.

288 Cancer was still regarded a stigma *'the condition'*, that is not talked about openly but is
289 discussed through gossip or side conversations in the social circle. Pity expressed by society
290 towards the patient elicited the perception of being weak, disempowered, and vulnerable. It
291 reinforced demoralization that did not resonate with dignity.

292 - *'Hmm...maybe...eh, when, for example, when you get sick, and people know that you are sick*
293 *they start looking at you in a different way...eh...in a way that they pity you...eh. this is ...I think*
294 *this is not right... eh... they start ...eh... labelling you. eh...which is ...eh... which in my opinion is*
295 *very wrong.'* Patient # 11

296

297

298 Theme Four: Accessible, equitable, compassionate, healthcare. *'The physician kissed me*
299 *on the forehead and told me nothing is wrong with me.'*

300

301 Compassionate, quality, and affordable health services enhanced participants' experiences of
302 dignity and indifference, or limited access demoted it. This theme also included the need for
303 clear communication, engaged physicians, respect for patient preferences, and equal access to
304 quality health care. A kiss on the forehead in Arabic cultures is associated with acknowledging
305 the grief of the other and aiming to provide comfort (49). Health providers who approached
306 participants with sensitivity and exhibited genuine caring, providing attention and hope for
307 better wellbeing, were regarded as fostering their dignity.

308 - *'The physician came to my room and asked about my wellbeing. I told him I had fever that day,*
309 *he told me "come, come", he kissed me on the forehead and told me "nothing is wrong with*
310 *you". He removed my leg stockings and told me to move my legs and start walking....'* Patient #
311 10

312

313 Participants wanted respectful and a non-judgmental approach during their health service

314 encounters expecting a physician who is competent and takes enough time to assess, listen and

315 then propose a plan of care. Physicians who were available to answer phone calls, performed
316 frequent ward rounds displaying an approachable attitude, and provided support to the patient
317 during chemotherapy sessions, were regarded as ideal in fostering dignity. In contrast,
318 physicians who remained distant in their posture or attitude, were volatile in their moods or
319 non-empathetic in their responses, hurried in their communications were not favored.

320 - *'For me it is important that a doctor is always a good listener and listens to all questions ...This is
321 what I want. These things comfort me. Sometimes they do not tell the truth the whole truth,
322 though there are physicians who explain all the phases of the disease' Patient # 13*

323
324 Information sharing was regarded to be an important aspect of care that enhanced dignity
325 irrespective of language, gender, or age. Clear and simple information about side effects of
326 treatment, chances of full recovery, the plan of care, upcoming procedures, was of utmost
327 importance to all participants to safeguard dignity during health encounters. Hiding information
328 or not fully disclosing all aspects of care was disappointing and diminishing to patient dignity.
329 One participant was skeptical about the non-convincing explanations of a physician when he
330 asked about potential complications of radiation therapy on his sexual health.

331 - *'Once I told him (the doctor) that my energy is low as a male, my energy is low, he told me till
332 we finish the treatment, then you will be like a horse. But, when do we finish the treatment?
333 Pause.... He had told me that this is my treatment for the rest of my life, is he deceiving me? or
334 cheating on me or giving me a satisfying answer so that he is acceptable'* Patient # 2

335
336 A variation in the quality of care or access to medicine was a concern for participants who could
337 not afford to pay or were not politically affiliated. As most health services were privatized and
338 expensive, the socioeconomic status or the power to afford services categorised participants as
339 privileged, or less advantaged to access quality, timely, and expert care, or medicine.

340 - *'At this hospital, outpatient health care depends on time spent with the physician, sometimes*
341 *physicians don't spend sufficient time with the patient, and this is not fair, and a very bad thing.*
342 *If you have a long session, they charge a specific high fee, and if a short session they charge*
343 *less'. Patient # 8*

344

345 These occurrences were interpreted as unjust, violating patient rights and diminishing the
346 dignity of those who could not afford it.

347 - *'If anyone belongs to a religious group, he is admitted to the hospital easily, Also, if you are a*
348 *politician or something important, you will have no problem with the hospitals... it's a big deal'.*
349 *Patient # 11*

350

351 Discussion

352

353 The study highlights that participants had a fluid understanding of dignity and struggled to
354 define it, but they found that faith, religious beliefs, and moral values contributed to its
355 enhancement. They believed that dignity is an inherent human feature, not dependent on
356 health status. Illness was seen as a natural part of life and did not necessarily diminish dignity;
357 participants suffered from the physical impact of illness it had on their life. The study also
358 stresses the importance of family and children in preserving dignity during illness. Having a
359 supportive caring family, especially children, reinforced dignity and provided a sense of pride
360 and identity. Patients found a safe refuge in their families during their most vulnerable times
361 that was often associated with a chain of losses. Being embraced and taken care of through
362 family network restored personal dignity. Participants aspired to restore physical, social, and
363 mental well-being to reclaim their dignity and normalize their lives. Challenges related to
364 physical appearance, memory loss, vitality, and social stigma associated with illness diminished

365 dignity. Finally, the study emphasizes the significance of compassionate and affordable
366 healthcare services in preserving dignity. Participants valued clear communication, respect, and
367 empathy from healthcare providers, and identified affordability and equal access to quality care
368 essential for maintaining dignity.

369 The idea that dignity is elusive and difficult to define is aligned with other research findings (8,
370 50, 51). Restoring dignity through faith in God and prayer can be seen as nurturing a sense of
371 solace, reconciliation, and perseverance in some United States' (US) and Chinese communities,
372 too (52-55). Religious rituals and traditions were major coping mechanisms of patients rooted in
373 the daily routine upholding a sense of wellbeing and dignity. Patients longed for having peace
374 with their creator and observing religious set of values which was a part of broader sense of
375 spirituality but emphasized through commitment and faith in deity.

376 In Asian and African communities, dignity is at a dynamic interplay, often reciprocal, intertwined
377 with the empathetic bonds and sense of connectedness (56) within the patient's immediate
378 family and their children (13, 15, 57). In Western studies, the concept of individual autonomy
379 and self-determination takes precedence (58, 59), whereas in collective societies, a familial
380 approach to dignity is more prominent (56, 60, 61). Participants in communal cultures such as
381 Lebanon, perceive family and children as essential to securing their own dignity and personal
382 legacy (61, 62). Family members and children are often the primary caregivers, creating a safe
383 space for healing and maintaining a sense of value in times of vulnerability (15, 57).

384 Across various regions including the U.S, Canada, Asia, and Europe, research participants
385 consistently associate a positive sense of dignity with autonomy, the ability to carry out daily

386 activities independently(63, 64) , and communicate effectively with others (2, 59, 65-68).
387 However, the Lebanese culture, like the African, places a significant emphasis on outer
388 appearance and physical fitness, assuming any decline in these aspects a threat to dignified
389 social interactions (69, 70). The stigma surrounding cancer compounds the distress, as physical
390 changes diminish dignity even leading to non-adherence to therapy(71, 72). It is relevant to
391 state that this research has adopted the social constructivist paradigm where knowledge is co-
392 constructed between the researcher and the participant and provides the subjective
393 perspective and voice of the Lebanese participants (27).

394 Patient dignity appears to be universally at risk when health providers fail to allocate sufficient
395 time for listening to patient needs, or rush through their interactions (73) (74, 75). Effective
396 communication beyond the rigid professional boundaries, using simple and kind language
397 seems to be a shared patient need in different parts of the world (73, 76, 77).

398 In Lebanon, the absence of universal health coverage creates a situation where access to quality
399 healthcare becomes a privilege for the affluent or well-connected, burdens the less privileged
400 subgroups financially and socially (78). This issue is not unique to Lebanon but is also observed
401 in other healthcare systems like the U.S., where socioeconomic wellbeing plays a crucial role in
402 accessing dignified healthcare services(79) . The lack of equitable access to healthcare highlights
403 the importance of addressing socioeconomic disparities and delivering equitable and inclusive
404 care to uphold dignity in the face of illness and healthcare needs.

405 In this section the findings are compared against the Chochinov Model of Dignity (80) that
406 comprises three main categories: a) illness related issues, b) dignity preserving repertoire, and

407 c) social dignity inventory. The themes of this study have an overall coherence with the
408 categories of the Chochinov Model with some variations in emphasis or interpretation. The
409 subthemes mentioned in the *Illness related issues* such as physical distress, maintaining physical
410 functionality, cognitive wellbeing are also important elements in maintaining dignity in the
411 Lebanese context. Nonetheless, two new sub-themes of dignity were identified in this study: a)
412 healthy outer appearance, and b) accessible, equitable care that does not appear in the
413 Chochinov model. Preserving a healthy physical appearance is a new theme key for preserving
414 self-image and thereby avoiding stigma related to the illness. Most participants expressed that
415 financial hardships and poverty limited access to needed resources indicating that economic
416 wellbeing is a precondition to maintaining dignity. In this regard, '*Accessible and equitable*' care
417 is crucial to preserve patient dignity while receiving health services, a theme missed in the
418 Chochinov model. Inequalities and health disparities among citizens based on social class
419 damages patient dignity as it restricts access to essential health services (81).

420 In addition, some of the sub-themes identified in the model hold a nuanced interpretation or
421 have a different emphasis such as 'social support', 'autonomy', 'role preservation',
422 'generalisability / and longevity'.

423 Faith and family support were the predominant coping practices through which patients
424 invoked inner strength, ('resilience'), and facilitated 'accepting the illness'. 'Resilience' and
425 'accepting the illness' are subthemes that existed in the model but without being related to
426 religious faith or family support. Presence of children and spouses helped preserve dignity as
427 they were seen as a source of 'pride' and 'legacy for life', again subthemes that existed in the
428 *dignity preserving repertoire* category of the model but without being related with family

429 support. 'Role preservation' in the traditional family hierarchy secured a sense of normality
430 where patient 'autonomy', a subtheme in the model was replaced with a 'relational autonomy'
431 among the family members. Due to the intense interdependence of the patient within the
432 family fabric, individualistic autonomy did not surface rather there was collective decision
433 making amongst the family members about health care issues in palliative care patients (82).
434 The theme of '*care tenor*' mentioned in the model was also regarded an essential element of
435 preserving dignity in this study where timely and clear information, and an authentic presence
436 with the patient enhanced dignity (83). The themes of being a 'Burden to others' and 'Aftermath
437 concerns' mentioned was not identified a pattern across the data probably because patients
438 believed it is the family members' duty to care for the sick

439

440 **Strengths & Limitations**

441 This research provides an initial understanding of the concept of dignity within palliative care
442 from an Arab- Lebanese perspective where the topic is unresearched. It reveals the unique
443 cultural understanding of dignity in patients with palliative care needs that may be useful to
444 inform practice, care, health education and policy in Lebanon and nearby countries with similar
445 geopolitical, and socioeconomic constructs.

446 Though telephone calls provided greater access to participants from remote areas and allowed
447 participants to discuss sensitive issues whilst maintaining confidentiality and privacy (84, 85),
448 participants' actual home environment was sometimes missed. Also, participants were
449 dominantly from a Christian community that may not reflect the religious dynamics of the

450 country, or those who may not identify with any religion. The findings were affected by the dire
451 socio-political and economic state of the country as well as the Covid-19 pandemic. Thus, it is
452 possible should there have been economic and political stability the findings may have had a
453 different emphasis. Implications of these findings for practice, policy and research are
454 elaborated below.

455 **Implications for practice:** The findings suggest that to enhance patient dignity, healthcare
456 facilities should prioritise family presence and visits, provide space for spiritual practices, or
457 spiritual referrals, and utilize digital applications to facilitate connecting with family and friends.
458 Healthcare providers need to demonstrate active engagement with the patients and
459 communicate full information about their choices of care and their implications. Healthcare
460 team members and staff should receive education about practices that enhance dignity,
461 tailoring interventions accordingly. Moreover, to foster a dignity-conserving culture, delivering
462 compassionate and inclusive care is paramount especially for those from different
463 socioeconomic backgrounds who may face barriers in accessing quality health services.

464 **Implications for Policy:** It is crucial that a national strategic plan for equal access to health care
465 is planned and implemented based on the principles of equity and social justice that funds
466 health care to all citizens. This could help reduce the social gap in accessing health services and
467 promote dignity within palliative care and overall health.

468 **Implications for research:** Exploring the perspective of health care providers regarding dignity
469 and compare it for coherence with patients' views is essential. Future studies that examine the
470 root causes or interventions to foster equity, social justice and dignity in health care would be

471 useful. Also, It would be interesting to pilot the patient dignity inventory-assessment tool (86)
472 and examine how dignity therapy (87), or dignity conserving interventions (88) work to
473 safeguard dignity in a Middle-Eastern culture.

474

475 **Conclusion**

476

477 This study highlights the multifaceted nature of dignity among palliative care patients in
478 Lebanon where familial, societal, and broader socio-political, religious factors shape its
479 understanding (89-91). Whilst conducted in Lebanon, the findings have implications to the
480 Middle East and potentially wider global community where understanding cultural context is
481 key in dignity-conserving care. Healthcare approaches that are mindful of the need of the
482 patient to connect with their religious beliefs and practices, family, and children must be
483 considered. Compassionate presence, clear communication and equitable access to care are
484 fundamental aspects of the health care services that promote patient dignity in palliative care
485 settings.

486

487

488 **Declarations**

489

490 **Ethics Approval & Consent**

491 All methods were performed in accordance with the Declaration of Helsinki (92). The research was
492 conducted in Lebanon and was part of the first author's PhD thesis project. Ethical approvals were
493 secured from the American University of Beirut Institutional Review Board (IRB- ID: SBS 2020-0033) and
494 Lancaster University Faculty of Health & Medicine Research Ethics Committee (FHMREC19139)

495 **Consent for publication**

496 Not applicable.

497 Availability of data and materials

498 The datasets generated and/or analysed during the current study are not publicly available due
499 participant confidentiality and privacy but are available from the corresponding author on reasonable
500 request.

501 Competing interests

502 The authors declare that they have no competing interests.

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509 Author contributions

510 SDS conceptualized the idea and developed the protocol with input from NP and YS; SDS conducted the
511 interviews and led the analysis of the data with support from all authors. SDS wrote the first draft of the
512 paper. NP and YS contributed to its critical revision and refinement. All authors read and approved the
513 final manuscript.

514 Declaration of conflicting interests

515 The author(s) declare no potential conflicts of interest with respect to the research, authorship, and/or
516 publication of this article.

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