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*Published in:*  
Nursing Ethics

*DOI:*  
[10.1177/0969733018796679](https://doi.org/10.1177/0969733018796679)

Published: 01/11/2019

*Document Version*  
Peer reviewed version

[Link to publication on the UWS Academic Portal](#)

*Citation for published version (APA):*

Mohammadi, F., Rakhshan, M., Molazem, Z., Zareh, N., & Gillespie, M. (2019). Caregivers' perception of dignity in teenagers with autism spectrum disorder. *Nursing Ethics*, 26(7-8), 2035-2046.  
<https://doi.org/10.1177/0969733018796679>

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Mohammadi et al, Caregivers' perception of dignity in teenagers with autism spectrum disorder, *Nursing Ethics*, Volume number 26, Issue number 7-8, pp. 2035-2046. Copyright 2019 Sage Publications. DOI: <https://doi.org/10.1177/0969733018796679>

# Caregivers' Perception of Dignity in Teenagers with Autism Spectrum Disorder

## Abstract

**Introduction:** Respecting the dignity of patients is one of the main ethical responsibilities of caregivers. However, in many cases, the dignity of patients, especially autistic teenagers is not maintained. The extent to which dignity needs are met for this group within the Iranian care system is difficult to determine as dignity is an abstract concept, and there are few related research studies reported.

**Objectives:** The objective of the present study is to find out what dignity means for autistic teenagers from the perspective of their caregivers.

**Research design:** This study uses a qualitative research design. The data was collected through individual, semi-structured interviews and field notes developed during the interviews. In order to analyze the data qualitative conventional content analysis was used.

**Participants and research context:** Sixteen professional caregivers for autistic teenagers working in public hospitals were recruited based on a targeted sampling method to reach data saturation from February 2016 to July 2017.

**Findings:** The findings of this study were presented in three main themes, "privacy", "respecting individual identity" and "comprehensive support", and 11 categories.

**Ethical consideration:** This study's protocol was approved by the Research Ethics Committee of medical universities located in Southeast of Iran and the required ethical principles were followed throughout.

**Discussions and conclusion:** Based on the findings of the present study from the perspective of caregivers, autistic teenagers need to be cared for and educated in a respectful environment where their privacy is maintained, their individual identities are respected and they receive comprehensive familial, social and financial support. These conditions would maintain the dignity of such teenagers and would result in appropriate behavioral outcomes. Therefore, it is suggested that a cultural, professional and institutional background in which all components of the autistic teenager's dignity are protected and emphasized be provided

**Keywords:** Dignity, autism, teenager, qualitative research

## 34 Introduction

35 Maintaining the dignity is one of the fundamental human rights <sup>1</sup>. The term dignity has a lot of  
36 meanings, the most important of which are: value, honor, humanity, status, and respect <sup>2</sup>. The word  
37 "dignity" has increasingly become a part of contemporary discussion on health care <sup>3</sup>. Because an  
38 illness can create a background in which a person's dignity might be violated, all patients need to  
39 have their dignity maintained, even under adverse circumstances <sup>4,5</sup>. Therefore, maintaining and  
40 respecting the patients' dignity is one of the main rights of patients receiving healthcare <sup>6</sup>, and is  
41 also one of the moral responsibilities of caregivers <sup>7</sup>. The WHO states that all patients are entitled  
42 to receive treatment which maintains their dignity <sup>8</sup>. Therefore, many national and international  
43 nursing organizations have considered dignity of patients as one of the basics of caregiving <sup>9,10</sup>.

44 Respecting a person's dignity results in an increase in their satisfaction with care provided,  
45 improves the relationship between the caregiver and the patient, and also enhances the caregivers'  
46 motivations in providing their care <sup>11</sup>. However, some studies have mentioned that patients are  
47 vulnerable to losing their dignity within caregiving environments <sup>12,13</sup> and some of the recent  
48 studies have reported a lack of privacy, respect and dignity within such environments <sup>14</sup>.  
49 Maintaining patient dignity is a crucial factor in guaranteeing high quality care delivery; therefore,  
50 understanding the concept of dignity from the perspectives of the patients or the caregivers makes  
51 the treatment process easier and enhances the psychological safety of the patients. Sufficient  
52 research is therefore required in order to fully explain the concept <sup>12,14</sup>. Based on available studies,  
53 dignity is a complicated and multidimensional concept and therefore cannot have a simple  
54 definition <sup>13</sup>. Despite attempts to define this concept and identify its effective elements, the concept  
55 of dignity and its related factors remain complicated and unclear <sup>15</sup>. Since maintaining dignity  
56 cannot be confirmed without the concept being clearly defined <sup>16</sup>, a need has been recognized to  
57 define this concept and to identify the effective elements of dignity among patients with different  
58 diseases and disorders <sup>13</sup>.

59 People with intellectual and developmental disabilities, especially autistic children and teenagers,  
60 are more vulnerable to being ignored, abused, and not having their dignity maintained within  
61 caregiving environments <sup>17,18</sup>. Autism is one of the developmental disorders and according to recent  
62 research, this disorder has increased more than 6% throughout the world, creating significant  
63 challenges for caregiving organizations <sup>19</sup>.

64 Review of the related literature shows that dignity has been examined in specific categories of  
65 patients such as: cardiovascular patients <sup>20</sup>, end of life-stage patients <sup>21</sup> as well as hospitalized  
66 teenagers <sup>22</sup>. However, this concept has not been defined for autistic teenagers. Due to their  
67 developmental and behavioral disorders, this group of patients are more vulnerable to be ignored  
68 and lose their dignity when in formal caregiving environments. Also, the results of the studies on  
69 other patients cannot be generalized to patients with intellectual, developmental or behavioral  
70 disorders, because the physical environment, organizational culture and the behaviors and  
71 perspectives of the care staff can affect dignity <sup>23</sup>. Thus, studies conducted among other patient  
72 groups cannot be generalized to autistic teenagers cared for within residential settings. On the  
73 other hand, the possibility of examining the concept of dignity from the perspective of autistic  
74 teenagers is difficult and ethically concerning, due to their developmental, behavioral and language

75 disabilities. The caregivers of autistic teenagers are the most important and closest people to these  
76 teenagers; they spend long periods of time with these teenagers and have the most information  
77 about them. Hence, the aim of the present study was to explore the concept of dignity in teenagers  
78 with autism spectrum disorder from the perspective of Iranian caregivers, with a view to preserving  
79 and improving these teenager's dignity within health systems, and to reflect the necessity of  
80 exploring dignity in public health care settings in Iranian society.

81 Qualitative studies can help explain a phenomenon in the cultural context of people's perspectives  
82 who deal with a phenomenon for a long time<sup>24</sup>, so this approach was selected in order to explain  
83 caregivers perspectives of dignity among autistic teenagers. It is hoped that the results of this study  
84 can help managers and caregivers provide an environment which supports dignity and the rights  
85 of teenagers.

86

### 87 **Objectives**

88 The aim of the study is to explore the concept of dignity among autistic teenagers from the  
89 perspective of those caring for them.

90

### 91 **Methodology**

92 In this research, the authors are trying to explore dignity for looked after autistic teenagers from  
93 the perspective of their professional caregivers. Within qualitative research, reality is understood  
94 to be individually perceived, meaning a phenomenon can be understood through the commonalities  
95 and differences in how those closest to it make sense of it<sup>24</sup>. Therefore, a qualitative approach with  
96 conventional content analysis has been used to investigate this subject. Conventional qualitative  
97 content analysis is an appropriate procedure for obtaining reliable and valid results from textual  
98 data allowing the creation of new knowledge and innovative understanding of phenomena under  
99 investigation. In qualitative content analysis, the raw data is based on inference and interpretations,  
100 then it is summarized and placed into categories and themes 25-26.

101 Sixteen caregivers of autistic teenagers were interviewed, all of whom were working the in  
102 publicly funded centers providing care for autistic teenagers. These centers being affiliated to  
103 medical universities located in Southeast of Iran. Data gathering was performed from February  
104 2016 to July 2017. The criterion for inclusion consisted of being Iranian, speaking and  
105 understanding Persian, being 24-55 years old, having at least two years of work experience in  
106 caregiving centers for autistic teenagers, and the ability to provide appropriate and sufficient data  
107 on the subject. The caregivers were selected through purposeful sampling method and were invited  
108 to participate in this study.

109 In this study, data collection was conducted through individual interviews; in so doing 16 in-depth  
110 semi-structured interviews were conducted with the 16 caregivers. The interviews were carried out  
111 face-to-face in quiet environments with the cooperation and willingness of the participants. In  
112 addition, field notes were also used allowing collection of what the interviewer sees, feels and  
113 experiences, as this helps with analysis of the concept. The individual interviews first started with  
114 general questions such as: "what does dignity mean for autistic teenagers? In which situations is

115 the dignity of autistic teenagers at risk?” Based on the answers to these questions, follow-up  
116 questions such as “Can you explain more?” “What do you mean?” “Why did you feel so?” were  
117 asked. The interviews were carried out based on meeting the main objectives of this study. Also,  
118 if necessary, follow-up questions were used in order to increase and clarify information obtained,  
119 such as: “Can you explain more? Can you give me an example?” The interviews were recorded  
120 and field notes were taken with the permission and awareness of the caregivers. Each interview  
121 lasted between 45 and 90 minutes. Immediately after each interview, the interviews were listened  
122 to by the first author several times to develop a general understanding and deep insights, and then  
123 the interpretations (do you mean interviews?) were transcribed on paper. (Should this read  
124 “transcribed verbatim”) Data analysis was carried out after each interview, and later interviews  
125 were then scheduled. Interviews continued until the data was saturated. Saturation occurs when  
126 there is no new categories emerging and the categories are saturated based on their characteristics  
127 and dimensions <sup>27</sup>.

128 The data were analyzed simultaneously using the content analysis method; first each text was  
129 reviewed for immersion and acquiring insights and deep understanding around the phenomenon  
130 under study. Then meaning units were determined based on the objectives and the study questions.  
131 Next, important points were extracted as open codes, considering their clear and hidden meaning  
132 units. These codes were categorized under broader titles based on their similarities and differences,  
133 and the data analysis continued until the themes were extracted <sup>25, 27</sup>.

134 In order to ensure trustworthiness Graneheim and Lundman’s criterion were used <sup>28</sup>. At the  
135 beginning of the study, the researchers bracketed all their prior information and personal beliefs  
136 regarding maintaining dignity in the care setting I order to avoid the influence and interference of  
137 personal beliefs in the investigation of this phenomenon. To increase the reliability and validity of  
138 findings several techniques were employed including combining review of data sources (semi-  
139 structured interviews and field notes), prolonged engagement with the data, member checking, and  
140 peer checking. To do this, the extracted concepts and themes were submitted to 4 participants and  
141 2 peers; who stated that the findings were in line with their understandings and interpretations.  
142 Furthermore, the researcher limited the textual reviews in order to reduce bias in collecting,  
143 analyzing and coding of the interviews to increase the validity of the date. Finally, Confirmability  
144 was acquired through exact recording of participant narratives and detailed reporting of the study  
145 to provide the possibility of follow-up for other researchers.

146

## 147 **Ethical Considerations**

148 The institutional review board of the medical universities located in Southeast of Iran provided  
149 ethics approval (approval number: 95-01-08-1168). Also, at the beginning of each interview, the  
150 researcher introduced herself and explained the aims of this study, and informed consent was  
151 obtained after providing verbal and written explanations. The participants were assured that all  
152 information would remain confidential. The researcher created the opportunity for participants to  
153 inform the researcher about their withdrawal from the study at any stage of the study and assured  
154 them that their lack of participation or withdrawal would not have any consequences for them.

155

156

157

## 158 **Results**

159 In this study interviews with 16 caregivers of autistic teenagers living in public health centers were  
160 carried out. The participants of this study included 10 women and 6 men. The individual  
161 characteristics of the participants are presented in Table 1.

162 The three main themes emerging from these interviews were privacy, respecting individual  
163 identity, and comprehensive support while 11 categories were extracted from the data. Table 2  
164 presents the themes and categories. Dignity for teenagers with autism spectrum disorder is  
165 consequently defined as the preservation of privacy; respect for individual identity and the  
166 delivery of comprehensive support for these teenagers.

167

### 168 **A) Privacy**

169 The participants in this study stated that maintaining the sexual, physical, psychological and  
170 information privacy of autistic teenagers receiving care in in publicly funded care centers is very  
171 important in order to maintain their dignity. therefore, the caregivers respect the patients' privacy  
172 and try to maintain it. The privacy theme included four categories: maintaining physical-sexual  
173 privacy, maintaining psychological privacy, maintaining information privacy, and respecting the  
174 possessive rights of autistic teenagers.

175 The participants in this study reported that due to the patients developmental, behavioral and  
176 intellectual disorders, and the high prevalence of reports of physical and sexual abuse of such  
177 teenagers, it is essential that they be taken care of by same-sex caregivers.

178 *"Frequently, when delivering care, some parts of the autistic teenagers' bodies, especially*  
179 *their sexual organs might be exposed and obviously. based on these teenagers' disorders if the*  
180 *caregiver is the same-sex, it would be safer"* (Female, 42 years old).

181 They also said that due to behavioral disorders, such teenagers might show abnormal behaviors  
182 which might threaten the physical or sexual privacy of themselves and other people. Therefore,  
183 it is essential that autistic teenagers of the same-sex reside together within shared  
184 accommodation.

185 *"Sometimes these teenagers show certain behaviors: they take off their clothes in their*  
186 *room in the health center; thus, they may threaten the physical and sexual privacy of*  
187 *themselves or their roommates. So keeping teenagers of the same sex in one room can*  
188 *help support their privacy."* (Male, 38 years old).

189 The caregivers insisted that male teenager should be wearing his pants (trousers) to maintain his sexual  
190 and physical privacy. The researcher overheard the following conversation in a center providing care for  
191 autistic teenagers:

Caregiver: Put on your pants immediately.

Teenager with aggression: I will not

Caregiver: If you wear pants, you can play with others

He subsequently wears pants with the help of a caregiver

192 Caregivers emphasized that care should be delivered by staff of the same gender as the patient, in order  
193 to maintain their sexual and physical privacy. The researcher overheard the following within a center  
194 providing care for autistic teenagers:

Supervisor: How many adolescents are hospitalized ?

Caregiver: 6 boys and 4 girls. That means we need 3 male caregivers and 2 female  
caregivers.

Supervisor: ok

195 Some of the caregivers also mentioned that it is important to respect the psychological privacy of  
196 these teenagers; when teaching appropriate behaviors, we should pay attention to their  
197 developmental status and not use their disabilities in a way that destroys their personality or self-  
198 esteem.

199 *“Caring and educating these teenagers is difficult. Sometimes the caregivers ignore their*  
200 *developmental and physical disorders while educating them, and when these teenagers*  
201 *get aggressive and quarrelsome, they will be stigmatized with inappropriate labels; even*  
202 *mentioning their disabilities can really ruin their self-esteem” (Female, 30 years old).*

203 In addition, the participants in this study stated that the personal information and the personal  
204 lives of these teenagers and especially history of sexual rape or abuse should not be recorded in  
205 their files, but should be rather kept confidential by the head nurse or the doctor of the caregiving  
206 center.

207 *“Although it is important to keep all the teenagers’ information confidential, it is*  
208 *apparent that in our country there is a negative view toward abuse, especially sexual*  
209 *assault, and sometimes the file might be studied by people other than the medical staff;*  
210 *therefore, it is essential that such information be kept confidential by the person in*  
211 *charge” (male, 28 years old).*

212 The participants in this study also said that the caregivers should respect the rights of these  
213 teenagers around use of their personal items and accessories.

214 *“Although these teenagers have developmental and behavioral disabilities, the*  
215 *caregivers should respect them and understand that they do not have the right to take*  
216 *one of the teenagers’ possessions and give it to another teenager without their permission.*



217 *Sometimes the caregivers do this, which results in arguments or fights among teenagers or*  
218 *arguments between the teenager and the caregiver” (male, 40 years old).*

219

## 220 **B) Respecting individual identity**

221 The caregivers who participated in the study stated that it is an ethical principle to respect  
222 religious and age identity of autistic teenagers. Also, the caregivers should avoid pity and  
223 discrimination in order to maintain the dignity of these teenagers, and should care for such  
224 teenagers fairly. This theme included the four categories of respecting age identity and religious  
225 identity of autistic children, avoiding pity and discriminatory behaviors.

226 One of the moral principles of nursing care is respecting the age and religious identities of the  
227 people receiving care in order to provide appropriate care.

228 *“These are not kids. These teenagers have good physical development and they have*  
229 *grown up and we should respect their maturity and age” (Female, 28 years old)*

230 *“These teenagers possess different religious beliefs and I, as a caregiver, respect the*  
231 *identity and religious needs of these teenagers and their families, and respect what they*  
232 *say even if I dont agree with their beliefs” (Female, 28 years old).*

233 Caregivers also suggested that it is essential to avoid any unnecessary pity in order to promote  
234 patient dignity.

235 *“It’s not appropriate to demonstrate unnecessary pity while educating and caring for these*  
236 *teenagers, working over sympathetically and being guided by extensive levels of*  
237 *unnecessary compassion can destroy their personality and makes us unable to perform our duty*  
238 *to educate them appropriately” (male, 38 years old).*

239 In addition, it is vital that the caregivers avoid demonstrating any discrimination when caring for  
240 these teenagers and even parents should avoid any discrimination between autistic teenagers  
241 and other teenagers in the family and approach them each fairly.

242 *“Sometimes families differentiate between autistic teenagers and their siblings and pay*  
243 *less attention to these teenagers and their needs and pay more their attention to their fit*  
244 *and well teenager and therefore are discriminating toward their children” (male, 30*  
245 *years old).*

246

## 247 **C) Comprehensive support**

248 Based on the statements of the participants, comprehensive support for autistic teenagers  
249 is one of the most important dimensions for creating and promoting dignity for this client  
250 group, therefore, it is necessary that these teenagers be provided with comprehensive

251 familial, social and financial support. This theme includes three categories: familial support,  
252 financial support and Social awareness support.

253  
254 The participants in this study stated that familial support and especially the respect that the  
255 parents consider for such teenagers is the most effective factor promoting their dignity.

256 *“The parents of some autistic teenagers are so respectful toward their teenager and*  
257 *they are so patient toward the teenager’s aggressive behavior, also important is*  
258 *appropriate training and education, which unconsciously makes all caregivers and*  
259 *even the relatives of these teenager more likely to behave politely with them. I think*  
260 *the support and demonstration of respectful behavior by the family with these*  
261 *teenagers has the biggest effect on maintaining dignity of the teenagers by others”*  
262 *(female, 41 years old).*

263 Furthermore, the participants reported that if people in general are aware of the persons illness  
264 and know that the inappropriate behavior of these teenagers is due to that, they are likely to have  
265 more appropriate reactions toward the teenager’s behavior and therefore their dignity will be  
266 maintained within that society.

267 *“These teenagers will demonstrate a lot of inappropriate behavior in public and crowded*  
268 *places and because of the lack of awareness about their disorder; people would chastise*  
269 *autistic teenagers and their caregivers verbally and make them feel uncomfortable,*  
270 *alienated and sad. Therefore, if public awareness is increased, people are likely to*  
271 *respond moree helpfully in reaction to such inappropriate behavior , maintaining the*  
272 *patients dignity” (Female, 32 years old).*

273 The participants also added that caring for autistic teenagers attracts a significant financial burden  
274 for families. As a result, there is a lot of ignorance in educating and caring for such teenagers and  
275 this will violate the dignity of such teenagers at present and in future; so it is needed to have  
276 comprehensive financial support of these teenagers by their families or public organizations in  
277 order to promote their dignity.

278 *“Autistic teenagers need to be educated for a long time. Because without extensive*  
279 *education, their social skills will not improve and they won’t be able to live independently;*  
280 *consequently, their dignity will be damaged. On the other hand, providing prolonged education*  
281 *will require large sums of funding. Hence, financial support for these teenagers by*  
282 *governmental organizations is needed” (male, 27 years).*

283

## 284 **Discussion**

285 Human dignity is an important concept in nursing and professional caregiving, and it is one of the  
286 fundamental human rights<sup>29</sup>. Since teenage patients are more vulnerable, their dignity tends to  
287 be more at risk, compared to other groups of patients. Therefore, because of their behavioral and  
288 developmental disabilities, can be claimed that dignity of autistic teenagers is more at stake

289 compared to other hospitalized teenagers, the findings of this study emphasizes the importance  
290 of maintaining dignity among autistic teenagers. In this study, maintaining dignity of autistic  
291 teenagers from the perspectives of caregivers included three main themes: privacy, respecting  
292 individual identity, and comprehensive support.

293 The concept of dignity in autistic adolescents has not been explored and defined, Therefore, Due  
294 to the lack of relevant studies the findings of this study were discussed with the findings of others  
295 studies that were explored the concept of dignity on other patients' population.

296 Privacy is fundamental to human dignity; it is essential to respect the patient's privacy, especially  
297 hospitalized teenagers. The present study, based on the perspectives of caregivers for autistic  
298 teenagers, revealed that maintaining the physical-sexual, psychological, informational privacy and  
299 respecting the possessive rights of teenagers suffering from autism is of great importance. The  
300 human dignity is a concept related to the culture, also all caregivers of the present study were  
301 Muslims and Iranians and they believe that hospitalized teenagers should also respect the Islamic  
302 laws. Furthermore, these caregivers knew that physical-sexual issues were of great importance in  
303 Iranian culture and especially rape threatened the personal and familial dignity. Therefore,  
304 caregivers tried to keep teenagers of the same sex in one room and also provide professional care  
305 by a person of the same sex in order to maintain their dignity. Three related studies also revealed  
306 that maintaining physical-sexual privacy among hospitalized adolescents is very important in  
307 order to maintain their dignity<sup>22, 30, 31</sup>. In accordance with the findings of the present study,  
308 caregivers should respect the psychological privacy of these teenagers; especially when teaching  
309 correct behaviors to these teenagers. A lot of related studies have examined psychological and  
310 psychological abuse toward children and teenagers with developmental and intellectual disorders  
311 such as autism<sup>32-34</sup>. In this regards, Reiter's study reports that children and teenagers suffering  
312 from developmental and mental disorders are very vulnerable toward stigma, ignorance and  
313 psychological abuses<sup>35</sup>. Caregivers of the present study stated that personal, clinical, and familial  
314 information of autistic teenagers should be quite confidential especially the information related  
315 to the teenager's sexual abuse should be kept in locked file by head nurse, and should be given  
316 to the medical staff only if necessary. One study in Iran on hospitalized teenagers reported that  
317 maintaining the information privacy of hospitalized teenagers from their perspective is one of the  
318 most important aspects of privacy; these teenagers share their information only with their nurses  
319 and avoid revealing their personal information to other people, which reveals the importance of  
320 this aspect in maintaining the privacy of patients <sup>22</sup>. Respecting the possessive rights of autistic  
321 teenagers is another category related to the theme of privacy in the present study. The caregivers  
322 in the present study stated that although due to behavioral and developmental disorders the  
323 autistic teenagers are unable to participate in caregiving decisions, and such decisions are mainly  
324 made by their families and the medical staff, still their possessive rights about their bodies and  
325 personal items should be respected and their bodies and personal items should not be touched  
326 without their permission. Respecting the possessive rights was referred to as protection of  
327 autonomy in other studies; this difference can be due to the developmental-behavioral  
328 disabilities of autistic teenagers and the lack of their ability in order to participate in medical  
329 decision-making. Therefore, maintaining the physical-sexual, psychological, informational privacy

330 and respecting the possessive rights of these teenagers are necessary for improve the quality of  
331 care.

332 Respecting the personal identity is another theme of dignity among autistic teenagers in the  
333 present study. Respecting the individual identity in the present study emphasizes respecting the  
334 age and religious identity, avoiding pity and discrimination behaviors in order to develop the  
335 dignity among autistic teenagers. The participants of this study believed that they needed to  
336 respect the age identity and different religious beliefs of autistic teenagers and their families, and  
337 should try to meet the religious and spiritual needs of such teenagers. A number of related  
338 studies mention the importance of respecting the personal identity by the medical staff as one of  
339 the important aspects of ethical care 36, 37, Therefore nurses and other caregivers should respect  
340 the patients' national, religious, racial and age differences, and should provide the care without  
341 any discrimination <sup>38</sup> 39- 40. Furthermore, the caregivers of this study reported that pity behavior  
342 toward these teenagers should be avoided, because such behavior can interfere with the  
343 education and caregiving and consequently destroy the self-esteem of these teenagers and  
344 threaten the dignity of autistic teenagers. Other studies also stated pity toward patients can have  
345 adverse effects on the patients' psychological attitudes and their dignity <sup>41-43</sup>. Avoiding  
346 discrimination is also another important category related to the theme of respecting personal  
347 identity. Participants of this study stated that caregivers should not differentiate between autistic  
348 teenagers; even the parents of such children should not differentiate between autistic children  
349 and fine children, because it results in threatening the dignity of autistic teenagers. Also avoiding  
350 discrimination is a professional value in nursing; caregivers should pay attention not to have  
351 discrimination between patients. two other studies also state that there are a lot of evidences  
352 that caregivers differentiate between patients and this ethical values are ignored by caregivers  
353 <sup>44, 45</sup>.

354 Another theme in this study is comprehensive support of autistic teenagers. The caregivers who  
355 participated reported the comprehensive support of the autistic teenagers is one of the main  
356 needs of such teenagers in order to improve their dignity. These teenagers needed  
357 comprehensive familial support in their physical and psychological aspects; social awareness  
358 support and financial support. A lot of studies have examined the importance of social and  
359 familial support of adolescents; all of them state that such support will enhance the teenager's  
360 ability to cope with present situation and improve teenager's behavior <sup>46</sup>. However, most studies  
361 among autistic children and teenagers have examined the importance and effects of familial  
362 support and social support of the parents as main caregivers of such children and teenagers <sup>47, 48</sup>.  
363 Bilgin et al. state that professional and social support will reduce the parents' worries and fears  
364 about their autistic children and teenagers <sup>49</sup>. It is obvious that if the parents of such children and  
365 teenagers have the familial and social support, they will be more competent in order to care for  
366 their disabled children and teenagers. Also they can better maintain and improve the dignity of  
367 teenagers suffering from developmental and intellectual disabilities. Furthermore, the  
368 participants of this study added that caring for such children imposes a lot of expenses; thus  
369 financial support of public centers is important. Although, many developed countries have  
370 centers and communities for the financial support of disabled children and teenagers. But in most

371 developing countries, especially Iran, there are not public centers which support these teenagers  
372 and their families financially due to the adverse economic situations.

373 Finally, it can be said that one of the most important care needs of autistic teenagers is to preserve  
374 their dignity. The caregivers participating in the present study felt the dignity of these teenagers  
375 has been preserved when they were cared in a respectful atmosphere with preservation of their  
376 privacy and had also receive the comprehensive familial, social and financial support.

### 377 **Limitations and suggestions**

378 One of the limitations of the present study was that the caregivers of the autistic teenagers  
379 were only from public centers. The selection of the participants from private centers could  
380 improve the generalizability of the findings. Another limitation of this study was the collection  
381 of data through individual interviews and field notes; making use of other data collection  
382 methods could enrich the results of this qualitative study. Therefore, it is suggested that futures  
383 studies examine the dignity of autistic teenagers and teenagers with other developmental or  
384 behavioral disorders in private centers also in addition to individual interviews, other data  
385 collection methods such as observations and focus groups be utilized. Also, more qualitative  
386 and quantitative research on larger samples in other places and cultures is needed to explore  
387 the concept of dignity in autistic adolescents.

### 388 **Conclusion**

389 Autistic teenagers are more vulnerable to losing their dignity. Based on the fact that preserving  
390 dignity in teenagers can have desirable outcomes, dignity is of great importance, but dignity has  
391 not been defined in autistic teenagers. Findings of this study help to define this concept in this grope of  
392 patients. According to the results of the present study, providing a supportive atmosphere while  
393 respecting the autistic teenager's privacy and paying attention to their individual identity as well  
394 as can help to preserve their dignity. In addition, more emphasis on maintaining physical-sexual  
395 privacy and respecting the possessive rights of autistic teenagers along with comprehensive  
396 support in care helps improve the quality of care and promote of dignity in these teenagers.

397 Since human dignity is an essential value of nursing, especially in autistic adolescents. Therefore it is  
398 essential to provide the cultural, professional and organizational environment in which all the aspects of  
399 dignity of autistic teenagers are respected. Findings of this study can lead to pay attention to autistic  
400 teenager's dignity in nursing education in Iran, and Pediatric nurse specialist respect the dignity of these  
401 teenagers and are sensitive to this important issue. In addition the authorities and policy makers of  
402 health organizations should examine and use the findings of this study in order to provide appropriate  
403 environments regarding the dignity of these teenage in different aspects.

### 404 **Conflict of interest**

405 No conflict of interest was reported by the authors.

406

### 407 **Acknowledgment**

408 The present study is a result of the research project issued by medical universities located in  
409 Southeast of Iran, therefore the researchers wish to express their gratitude toward the authorities  
410 of Nursing and Midwifery Departments, and they also like to further thank the caregivers who  
411 participated in this study and other people who helped them carry out this research.

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## 421 **References:**

- 422 1. Michael L. Defining dignity and its place in human rights. *The new bioethics*. 2014; 20: 12-34.
- 423 2. Dehkhoda AA. Dehkhoda Dictionary (Vol. 8). *Tehran, Dehkhoda Dictionary Institute*. 1994.
- 424 3. Bagheri h, yaghmaei f and ashktorab t. Patient dignity and related factors: a qualitative meta-  
425 synthesis study. *Journal of Knowledge & Health*. 2011; 6.
- 426 4. Gustafsson L-K, Wigerblad Å and Lindwall L. Undignified care: Violation of patient dignity in  
427 involuntary psychiatric hospital care from a nurse's perspective. *Nursing ethics*. 2014; 21: 176-86.
- 428 5. Whitehead J and Wheeler H. Patients' experiences of privacy and dignity. Part 1: a literature  
429 review. *British Journal of Nursing*. 2008; 17: 381-5.
- 430 6. Berglund B, Anne-Cathrine M and Randers I. Dignity not fully upheld when seeking health care:  
431 Experiences expressed by individuals suffering from Ehlers–Danlos syndrome. *Disability and*  
432 *rehabilitation*. 2010; 32: 1-7.
- 433 7. Sizoo EM, Taphoorn MJ, Uitdehaag B, et al. The end-of-life phase of high-grade glioma patients:  
434 dying with dignity? *The oncologist*. 2013; 18: 198-203.
- 435 8. Organization WH. A declaration on the promotion of patients' rights in Europe. *Copenhagen:*  
436 *WHO Regional Office for Europe*. 1994.
- 437 9. Association AN. *Code of ethics for nurses with interpretive statements*. Nursesbooks. org, 2001.
- 438 10. Zahedi F, Sanjari M, Aala M, et al. The code of ethics for nurses. *Iranian journal of public health*.  
439 2013; 42: 1.
- 440 11. Sadeghi T and Dehghan Nayyeri N. Patients' dignity: patients' and nurses' perspectives. *Iranian*  
441 *Journal of Medical Ethics and History of Medicine*. 2009; 3: 9-20.
- 442 12. Ebrahimi H, Torabizadeh C, Mohammadi E and Valizadeh S. Patients' perception of dignity in  
443 Iranian healthcare settings: a qualitative content analysis. *Journal of medical ethics*. 2012: medethics-  
444 2011-100396.
- 445 13. Matiti MR and Trorey GM. Patients' expectations of the maintenance of their dignity. *Journal of*  
446 *clinical nursing*. 2008; 17: 2709-17.

- 447 14. Gallagher A, Li S, Wainwright P, Jones IR and Lee D. Dignity in the care of older people—a review  
448 of the theoretical and empirical literature. *BMC nursing*. 2008; 7: 11.
- 449 15. Adib-Hajbaghery M and Aghajani M. Patients dignity in nursing. *Nurs Midwifery Stud*. 2015; 4:  
450 e22809.
- 451 16. Baillie L, Gallagher A and Wainwright P. *Defending dignity: challenges and opportunities for*  
452 *nursing*. Royal College of Nursing, 2008.
- 453 17. Mandell DS, Walrath CM, Manteuffel B, Sgro G and Pinto-Martin JA. The prevalence and  
454 correlates of abuse among children with autism served in comprehensive community-based mental  
455 health settings. *Child abuse & neglect*. 2005; 29: 1359-72.
- 456 18. Slingsby B, Yatchmink Y and Goldberg A. Typical skin injuries in children with autism spectrum  
457 disorder. *Clinical pediatrics*. 2017; 56: 942-6.
- 458 19. Smith LE, Hong J, Seltzer MM, Greenberg JS, Almeida DM and Bishop SL. Daily experiences  
459 among mothers of adolescents and adults with autism spectrum disorder. *Journal of autism and*  
460 *developmental disorders*. 2010; 40: 167-78.
- 461 20. Moraveji M, Yaghmaei F and Bagheri H. Dignity of heart failure patients referred to Zanjan  
462 hospitals. *Journal of Health Promotion Management [Research]*. 2015; 4: 75-83.
- 463 21. Hemati Z, Ashouri E, AllahBakhshian M, et al. Dying with dignity: a concept analysis. *Journal of*  
464 *clinical nursing*. 2016; 25: 1218-28.
- 465 22. Jamalimoghadam N, Yektatalab S, Momennasab M, Ebadi A and Zare N. Hospitalized  
466 adolescents' perception of dignity: A qualitative study. *Nursing ethics*. 2017: 0969733017720828.
- 467 23. Nursing RCo. *Defending dignity: challenges and opportunities for nursing*. Royal College of  
468 Nursing London, 2008.
- 469 24. LoBiondo-Wood G and Haber J. *Nursing Research-E-Book: Methods and Critical Appraisal for*  
470 *Evidence-Based Practice*. Elsevier Health Sciences, 2017.
- 471 25. Elo S and Kyngäs H. The qualitative content analysis process. *Journal of advanced nursing*. 2008;  
472 62: 107-15.
- 473 26. Zhang Y and Wildemuth BM. Qualitative analysis of content. *Applications of social research*  
474 *methods to questions in information and library science*. 2016; 318.
- 475 27. Speziale HS, Streubert HJ and Carpenter DR. *Qualitative research in nursing: Advancing the*  
476 *humanistic imperative*. Lippincott Williams & Wilkins, 2011.
- 477 28. Graneheim UH and Lundman B. Qualitative content analysis in nursing research: concepts,  
478 procedures and measures to achieve trustworthiness. *Nurse education today*. 2004; 24: 105-12.
- 479 29. Hall P. Dignity and health. *The Lancet*. 2013; 382: 28.
- 480 30. Narayan K, Hooker C, Jarrett C and Bennett D. Exploring young people's dignity: A qualitative  
481 approach. *Journal of paediatrics and child health*. 2013; 49: 891-4.
- 482 31. Scott P, Vlimki M, Leino-Kilpi H, et al. Autonomy, privacy and informed consent 1: concepts and  
483 definitions. *British journal of nursing*. 2003; 12: 43-7.
- 484 32. Balogh R, Bretherton K, Whibley S, et al. Sexual abuse in children and adolescents with  
485 intellectual disability. *Journal of Intellectual Disability Research*. 2001; 45: 194-201.
- 486 33. Bowen E and Swift C. The Prevalence and Correlates of Partner Violence Used and Experienced  
487 by Adults With Intellectual Disabilities: A Systematic Review and Call to Action. *Trauma, Violence, &*  
488 *Abuse*. 2017: 1524838017728707.
- 489 34. Monteiro ACdS, Fernandes ATRS, Oliveira ABMd, Peixoto IVP and Pamplona MCdCA. Mothers'  
490 perspective on violence against children: constructing meanings. *Revista brasileira de enfermagem*.  
491 2018; 71: 34-9.
- 492 35. Reiter S, Bryen DN and Shachar I. Adolescents with intellectual disabilities as victims of abuse.  
493 *Journal of Intellectual Disabilities*. 2007; 11: 371-87.

- 494 36. Jo K-H and Doorenbos AZ. Understanding the meaning of human dignity in Korea: a content  
495 analysis. *International journal of palliative nursing*. 2009; 15: 178-85.
- 496 37. Slettebø Å, Caspari S, Lohne V, Aasgaard T and Nåden D. Dignity in the life of people with head  
497 injuries. *Journal of Advanced Nursing*. 2009; 65: 2426-33.
- 498 38. Faulkner J and Laschinger H. The effects of structural and psychological empowerment on  
499 perceived respect in acute care nurses. *Journal of nursing management*. 2008; 16: 214-21.
- 500 39. Büssing A and Koenig HG. Spiritual needs of patients with chronic diseases. *Religions*. 2010; 1:  
501 18-27.
- 502 40. Kang K, Im J, Kim H, Kim S, Song M and Sim S. The effect of logotherapy on the suffering, finding  
503 meaning, and spiritual wellbeing of adolescents with terminal cancer. *Journal of Current Directions in*  
504 *Psychological Science*. 2009; 312.
- 505 41. Jones J and Pattison S. Compassion as a philosophical and theological concept. *Compassion in*  
506 *nursing: theory, evidence and practice London: Palgrave*. 2016: 43-56.
- 507 42. Sinclair S, Beamer K, Hack TF, et al. Sympathy, empathy, and compassion: A grounded theory  
508 study of palliative care patients' understandings, experiences, and preferences. *Palliative medicine*.  
509 2017; 31: 437-47.
- 510 43. Solomon RC. Sympathy and Vengeance: The Role of the Emotions in. *Emotions: Essays on*  
511 *emotion theory*. 2013: 291.
- 512 44. Papastavrou E, Efstathiou G and Andreou C. Nursing students' perceptions of patient dignity.  
513 *Nursing ethics*. 2016; 23: 92-103.
- 514 45. Shafakhah M, Molazem Z, Khademi M and Sharif F. Facilitators and inhibitors in developing  
515 professional values in nursing students. *Nursing ethics*. 2018; 25: 153-64.
- 516 46. Pinkerton J and Dolan P. Family support, social capital, resilience and adolescent coping. *Child &*  
517 *family social work*. 2007; 12: 219-28.
- 518 47. Joosten AV and Safe AP. Management strategies of mothers of school-age children with autism:  
519 Implications for practice. *Australian occupational therapy journal*. 2014; 61: 249-58.
- 520 48. Safe A, Joosten A and Molineux M. The experiences of mothers of children with autism:  
521 Managing multiple roles. *Journal of Intellectual and Developmental Disability*. 2012; 37: 294-302.
- 522 49. Bilgin H and Kucuk L. Raising an autistic child: Perspectives from Turkish mothers. *Journal of Child*  
523 *and Adolescent Psychiatric Nursing*. 2010; 23: 92-9.

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**Table 1. Individual social characteristics of the participants**

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**Variable**

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**Gender**

Female

Male

**Education level**

Diploma of Nursing

Bachelor of Nursing

Bachelor of Psychology

Master of Nursing

Master of Psychology

**Marital status**

Married

Single

divorced

**Age**

Min- Max

Mean  $\pm$  Sd

**Work experience (years)**

Min- Max

Mean  $\pm$  Sd

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Min: Minimum; Max: Maximum; Sd: Standard deviation

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**Table 2. Themes and categories extracted from content analysis**

<b>Theme</b>	<b>Category</b>
<b>Privacy</b>	Physical-sexual privacy Psychological privacy Informational privacy Possessive privacy
<b>Respecting individual identity</b>	Respect for age identity Respect for religious identity Avoiding pity behaviors

Avoiding  
discriminatio  
n

**Comprehensive support**

Familial  
support  
Social  
awareness  
support  
Financial  
support

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