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Exploring young people's dignity: A qualitative approach

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Abstract

Aim: Human dignity as an important consideration in health care has been primarily investigated from an adult perspective. This paper explores young people's perceptions of dignity and how it impacts on their health-care experience.

Method: A qualitative pilot study was undertaken at the Children's Hospital, Westmead in from 2010 to 2011. Semi structured interviews were conducted with five inpatients, and data were analysed using a grounded theory approach.

Results: The adolescents interviewed perceived dignity as a way of protecting their personhood. Privacy and maintaining integrity were the means by which dignity could be preserved in a health-care setting.

Conclusions: The study found that young people had unique perceptions of privacy and personhood with regards to dignity. Of the concepts of dignity in the existing literature, the dignity of identity was most applicable to adolescents' conceptions. This understanding of young people's views of dignity could prevent dignity violations in health care and beneficially impact their development.

Keywords: adolescent; behavioural; ethics

What is already known on this topic

1. Dignity is a key component in human identity, and may positively or negatively affect self-perception.
2. Health-care situations can negatively impact on dignity and self-identity.
3. The establishment of a stable self-identity is a key developmental task of adolescence.

What this paper adds

1. Adolescents viewed dignity as a way of protecting their personhood and identity.
2. The concepts of privacy and maintaining integrity were uniquely described by adolescents as a way of ensuring dignity in health-care settings.
3. These findings may help tailor health care to best suit young people's needs.

The maintenance of human dignity is recognised as a core value in human interactions[1] and foundational to human rights.[2, 3] Dignity is of particular importance in health-care situations. Although it has been studied extensively from an adult perspective,[4] there are few studies of dignity in relation to children, generally or in relation to health care. This paper offers a beginning in this direction.

Academic literature analysing dignity[5] has identified three major dimensions that are key to understanding its importance in health care: the notion of *Menschenwürde* or intrinsic human worth; 'social dignity', which is created or destroyed through social interaction; and the dignity of identity, that which 'we attach to ourselves as integrated and autonomous persons',[6] including the ability to control one's body, the potential to create meaningful social interactions and the ability to articulate one's ideas.[7]

Any social interaction between people may potentially augment or damage the dignity of either party. Dignity violations can cumulatively lead to a loss of self-esteem and social isolation and, ultimately, impact adversely on mental and physical health.[5] The weakening of a person's 'core capacities' due to illness and/or negative experiences in health-care settings offers a significant risk of loss of dignity.[6]

To date, how (and whether) young people construe dignity has been little explored.[8] While the importance of devising health-care settings that promote young people's best interests is well recognised,[9] the significance of dignity to these patients appears unstudied to our knowledge, with the exception of one study that found health-care situations could result in maintained, restored or shattered dignity for paediatric patients depending on the presence or absence of hierarchical distinction.[10] This study showed that dignity violations occurred due to a lack of communication by health professionals and that dignity was maintained where there was open communication and collaborative interaction between practitioner and patients.[10] We agree with the authors of this study, but feel our understanding will be usefully extended by inquiring into how young people themselves view dignity and its importance in health care. The aims of the present study were to (i) investigate young people's perceptions of dignity; and (ii) consider how their perceptions of dignity impact on their health-care experience.

Methods

As we sought to uncover complex understandings of a complex concept, we considered a qualitative research approach most appropriate. We used tools drawn from grounded theory[11] to iteratively identify common themes within the data, which we then related to the current literature on dignity. However, this was not a purely grounded theory approach.

Interviews

A small pilot study of interviews with five participants was conducted at The Children's Hospital at Westmead (CHW) over 2010 and 2011. The study was part of a Bachelor of Medicine/Bachelor of Surgery honours project with limited time and scope; thus, five participants were considered sufficient for an initial investigation. Participants were recruited from inpatients at CHW aged between 12–16 years for ethical reasons and because of their capacity to discuss abstract concepts. Articulate and medically stable patients were suggested by staff and then approached by KN to gain informed consent from the parents and participants. Parents and participants were provided written information about the study; the content was identical, although language was slightly modified to address participants directly. Parents and

participants were informed that their data were confidential and all references to them in the paper would be de-identified with pseudonyms. Those who were highly dependent on medical care or with intellectual impairment were excluded. No one requested to participate declined to do so. To prevent bias, participants were not asked about reasons for admission or length of stay. The study was undertaken in accordance with the Declaration of Helsinki, and ethics approval was granted by the Royal Alexandra Hospital for Children Ethics Committee (approval number 09/CHW/145).

KN conducted a semi-structured interview lasting 15–30 min with each participant, exploring what dignity meant to the interviewee, based on the following questions:

1. Can you tell me what dignity means to you?
2. Since being in hospital, can you describe some situations which affected or involved your sense of dignity? When did you feel you were treated with dignity? When did you feel you were not treated with dignity?
3. Can you tell me about any incident or situation in hospital where, in your opinion, a person's sense of dignity would be involved?
4. Are there any changes you would suggest so patients' dignity was better respected in hospital?

An open-ended interviewing style was used in order to facilitate conversation about dignity and explore the individual ideas of participants.[12] To prevent bias in interpretation, participants were not asked about their reason for admission.

Interviews were conducted in a private area in the hospital such as a conference room in the ward. Parents could be present if desired, and were so in 60% of the interviews. The mother of one patient with dysarthria was instrumental in elaborating the participant's responses, but did not shift the focus of the interview from the participant's perspective.

Five female participants (names changed) – Alice, aged 16; Grace, 14; Rachel, 15; Isabelle, 16; and Caitlin, 16 – were interviewed. A qualitative approach to data analysis was employed, with both handwritten interview notes and audio recordings, which were transcribed, collated and analytically coded.[13]

Initial open coding was followed by an iterative process of formulating categories and exploring relationships between categories. Through a selective coding process, a central theme with two subcategories was identified.[13]

Results

The central theme identified was protecting personhood, with the subcategories of privacy and maintaining integrity. For the adolescents interviewed, dignity was essentially a means of protecting their personhood and individuality.

Privacy

Privacy was the dominant component of dignity for these adolescents. This was expressed both literally and metaphorically through the concept of 'personal space'. Some discussed hospital conditions, including the number of people per hospital room and their gender. Rachel, who had felt uncomfortable having tubes changed in a room with teenage boys, felt that it was necessary

to have single-gender wards of no more than four people. Caitlin believed that more than two in a room would be 'ridiculous' and 'putting a girl and a boy in a room would be stupid ... I wouldn't want to walk out to the shower in my pyjamas if there was a boy there'.

'Personal space' was more important in interactions with staff. Rachel, for example, described dignity as 'caution', explaining, 'If someone is going to do something for you, then respect your personal space and take caution and not bombard you and barge in and do it.' She described staff coming in and out while she was showering and feeling frustrated yet helpless to prevent it:

You're in the middle of doing something private and a whole medical team will come round ... and you're thinking 'Who the heck are they?' It's phenomenally intimidating.

For others, personal space was invoked as a means of retaining dignity during medical procedures. Alice's example of dignity violation referred to male nurses joking about changing her urinary catheter when she had specifically requested females. Grace felt that dignity could be encompassed by 'privacy and choice' and explained it as 'When I wasn't up to doing something, no one said you had to.'

Privacy could mean more than shielding one's body. Isabelle provided a multilayered analysis of privacy in which dignity was framed as a means of protecting self-identity and personhood. She spoke of the objectification of women in magazines like Playboy as an example of dignity violation; to her, the exposure of what she felt were private aspects of a person's life amounted to disrespect of their worth. Privacy also involved being able to speak to the doctor alone on issues she did not 'feel comfortable saying in front of parents', which displayed sensitivity towards and validated the adolescent's feelings.

Maintaining integrity

Caitlin framed integrity (having an intact sense of self and the agency that springs from this), rather than privacy, as the primary component of dignity. She defined dignity as the capacity 'to speak for yourself' and 'knowing that you can't be told what to do [or] be spoken to in a way that you don't want to'. She described a situation in hospital where she had been told to get out of bed but had refused because 'I had my own rights, I have my own dignity.' She felt she had been ordered to get out of bed. When asked how she felt upon asserting herself, she replied 'proud of myself'.

'Integrity' was a multivalent category that captured the participants' sense of needing to defend and achieve recognition for a complex and integrated sense of self. Rachel, for example, said that drawing the screen in the shower or having the medical team introduce themselves would have done much to make her feel valued, but that on many occasions, and especially because she had several medical issues, she felt she was viewed as a certain organ or body part rather than as a whole person. She also indicated how deeply integrity could be affected by humiliation when she described the ignominy of having to lie in bodily fluids while awaiting catheter and tube changes and trying hard to minimise the effect of 'aroma' on fellow patients.

Maintaining dignity

While all the participants were unhesitating about the importance of dignity in health care, they also reported positive experiences. Two participants stated that staff in the Adolescent Medical Unit knew 'how to treat teenagers': 'Sometimes they don't tell you what to do, they ask you nicely because they don't know how you're going to take it.' The manner of others was a key feature in dignity maintenance.

Indeed, the participants indicated that dignity violation could be prevented even in cases of intrusive medical care. Isabelle, for example, despite initial discomfort, did not feel demeaned by having to undress for examinations (unlike Rachel's experience) due to the professional manner and the respect accorded her, which she contrasted with 'objectified' exposure of women in magazines. Caitlin similarly mentioned measures such as drawing the curtain or only exposing whatever was necessary for the examination.

If violated, the participants indicated that dignity might be reclaimed through agency. For example, Rachel began to change and manage her own tubes and catheters. The relative independence that she achieved allowed her to re-establish her self-respect and dignity. Alice similarly refused to allow male nurses to change her urinary catheter and conveyed her disapproval when they joked about doing so. For Grace and Caitlin, being given a choice, as opposed to being told what to do, was important in maintaining their personal standards. Grace described an incident where she had asserted her wish not to go to hospital school when she was feeling 'teary', while Caitlin, as described above, ensured that she had a degree of control over her admission.

Personhood and identity

The participants universally constructed dignity as necessary to protect one's own sense of personhood and identity. Isabelle was explicit about this complex connection. She offered a definition of personhood that drew on Maslow's hierarchy of needs,[14] in which, however, creativity had primacy over security. In her opinion, creativity was a way of expressing personhood and dignity the concept which protected it. Thus, the 'horror' of living in slums was another way of violating dignity because it relegated humans to an 'animalistic' state and suppressed the higher needs in Maslow's hierarchy, which to Isabelle were key elements of a person's identity.

Rachel made the intimate connection between dignity and personhood the subject of personal action in her hospital situation. She and her mother decided to talk to and remember the names of the cleaners and ladies at the cafeteria, so that 'they're not just an anonymous person in a uniform doing a chore' and in order to respect 'who they are, what they do and giv[e] them identity'. This in turn resulted in the staff doing the same by Rachel: 'They respect me as a person, it's more of a relationship.'

Discussion

This pilot study was one of the first to directly question young people about their perception of dignity. It demonstrated that adolescent patients view dignity as a means of recognising their personhood. The two critical axes to their concept of dignity were privacy and integrity. They felt that instances described as dignity violations, such as intrusive gazes and lack of choice, 'objectified' them and made them feel vulnerable. Conversely, situations that preserved dignity were those that respected their agency and validated their self-worth.

The importance of privacy and integrity accorded with dignity scholarship. Rachel's situation, for example, embodied Nordenfelt's assertion that illness could undermine identity by imposing a dependence that was a 'violation of one's integrity'. [6, 8] Extending Popovich's observation of young children, lack of control over activities of daily living and bodily functions was regarded as humiliation and a loss of dignity.[8, 15] However, privacy as a way of protecting personhood was given an emphasis here that was not evident in previous dignity literature based on adult

perspectives. While adolescents' need for privacy has been recognised elsewhere,[16] its centrality to dignity in their eyes has not been explored.

The emphasis placed on identity by the adolescent participants was in agreement with Erikson's fifth stage[17, 18] as well as the recognised developmental task of adolescence of establishing a stable self-identity and achieving independence.[19] The desire for control over their bodies and medical management reflected the adolescent need to establish independence and was therefore an important component of dignity for these participants. Reasserting their personal standards was a way of wresting back control and an example of 'restored dignity'. [10]

Implications for health care

This study underscores the importance of dignity to adolescent patients, both in the experience of severe illness requiring care and because of the long-term impacts on their development. Patient concerns about privacy, particularly mixed-gender wards, offer a useful guide for planning and organisation of adolescent units in hospitals.[9] This study also reinforces research indicating[8, 10] that effective communication is critical for dignity maintenance in health care. It was positive to find that staff in particular medical settings (the adolescent ward) could cultivate modes of interaction that could overcome both intrusive medical requirements and resource limitations to maintain dignity for these patients. These modes of interaction prioritised conveying respect for the patient's agency, autonomy and sense of self, and self-worth. Such interactions are based on skill and experience that could be acquired and extended to general paediatric staff.

We note that challenging power structures and their own relative powerlessness was identified as important for protecting a vulnerable sense of personhood for our participants. This presents potential logistical, medical and ethical challenges in adolescent health care, since the assertion of autonomy and agency by an adolescent for whom these crucial developmental attributes have been, and remain, severely constrained by illness may not be in their best medical interests. For example, there may have been medical reasons for Caitlin being told to get out of bed. These interviews demonstrated how approach and manner might improve compliance with treatment. Adolescents viewed authoritarianism as a violation of dignity and need staff to join them in a balancing act between long-term medical benefit and promoting their developing self-concept.

Limitations and future directions

This study was limited to female participants purely as a result of the availability of suitable inpatients at the time of the interviews. Older patients were selected by staff for their ability to discuss such ideas in a semi structured interview format.

Theoretical sensitivity was increased in this study by exploring both dignity literature and developmental theories and by the iterative process of reflecting on and identifying relationships within the data.[11, 20] Furthermore, the combined perspectives of the authors, with backgrounds in qualitative research and medicine, respectively, provided unique insights.[20, 21] However, this was a small pilot study that was designed as an initial probe into young people's conceptualisation of dignity.

Clearly, the next step is for a study including a larger sample size and a greater diversity of patients in terms of gender, age, ethnicity and so forth, and one in which categories and concepts can be pursued to saturation.[11]

As only inpatients were included in this study, a similar investigation with non-hospitalised children and adolescents would illustrate how context affected young people's notions of dignity and consequently, how their best interests could be achieved overall in settings beyond the hospital.

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