Towards a Robot Computational Model to Preserve Dignity in Stigmatizing Patient-Caregiver Relationships

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Abstract. Parkinson's disease (PD) patients with an expressive mask are particularly vulnerable to stigmatization during interactions with their caregivers due to their inability to express affect through nonverbal channels [24]. Our approach to uphold PD patient dignity is through the use of an ethical robot that mediates patient shame when it recognizes norm violations in the patient-caregiver interaction. This paper presents the basis for a computational model tasked with computing patient shame and the empathetic response of a caregiver during "empathetic opportunities" [21] in their interaction. A PD patient is liable to suffer indignity when there is a substantial difference between his experienced shame and the empathy shown by the caregiver. When this difference falls outside of acceptable set bounds (norms), the robotic agent will act using subtle, nonverbal cues to guide the relationship back within these bounds, preserving patient dignity.

1 Introduction

In a patient-caregiver interaction, an experience of high rapport is deemed to be "optimal". The participants understand each other and are capable of appropriately responding to one another [23]. Tickle-Degnen [23, 24] has presented a substantial body of work showing the difficulties of those with expressive disorders to attain high rapport with their caregivers due to the critical role nonverbal communication plays in establishing such rapport. When caregivers are unable to attain rapport with their patients, they may stereotype their patients because of uncertainty about how the patient is feeling, which can lead them to stigmatize the patient [24]. A group particularly prone to stigmatization is Parkinson's patients with a condition known as an expressive mask that limits expressivity in their face, body, and tone of voice. Tickle-Degnen [24] has found that professionals who work with Parkinson's patients often misjudge these patients' personalities. Caregivers were found to judge patients showing higher masking to be less social, more depressed, and less cognitively competent.

In this five-year NSF-funded study, a collaborative interdisciplinary effort with Tufts University, our goal is to uphold the dignity of Parkinson's patients with expressive masks during stigmatizing interactions with their caregivers. One means by which this may be accomplished is to introduce an ethical social robot as a

bystander into the patient-caregiver interaction. This robot models the ongoing patient-caregiver relationship and uses subtle, nonverbal cues to guide the relationship [1] when norms of the interaction are violated. This paper presents the foundation for a computational model that is being implemented and tested in upcoming human-robot interaction studies; this model is intended to ameliorate patient indignity.

Dignity stands in opposition to stigmatization and the closely related concept of shame. Dignity is consistently linked with self-respect and identity [14]. The dignity of a person can, therefore, be "robbed" when he is humiliated. Humiliation causes a fundamental change in a person's understanding of his "identity" and place or worth in society [14]. The process of stigmatization culminates in the internalizing of a negative stereotype that is associated with some disease or disorder [16]. According to Sabini et al. [18], shame arises as a response in someone when a fundamental flaw is revealed because he sees this now public flaw as limiting his worthiness of positive relationships in the future.

The caregiver must respond to patient shame and stigma by making a connection with the patient; that is, showing patients that they are not alone and have value [21, 26]. If the caregiver does not respond empathically, this further confirms the patient's feeling of rejection, which results in increased feelings of shame, or in the development of resentment or anger toward the caregiver [26].

Therefore, a robotic agent mediating stigma needs to represent when the patient is experiencing shame and when the caregiver is not responding with a sufficient level of empathy. Section 2 in this paper discusses representations of shame and empathy based on the psychological literature. Section 3 presents a framework to preserve patient dignity. Section 4 summarizes and discusses how the project will progress from this point onward.

2 Shame and Empathy Representations

Shame is a construct that is not going to dissipate over the course of the communication between the patient and caregiver without intervention; shame is relieved through a change in "context" or a change in "self" [20]. Empathy from the caregiver affords this "context" change. The caregiver commits to being a present, social ally to the patient; the patient is made to recognize his value [26]. It is critical that the magnitude of shame that has been experienced by the patient during the interaction does not far outpace the empathy expressed by the caregiver.

It may not be possible for the caregiver to respond to the patient's shame with complete understanding and compassion in each "empathetic opportunity" [21]. The caregiver, however, needs to show sufficient empathy (while not showing too much) to keep the difference between the shame experienced by the patient and empathy shown by the caregiver during the interaction within acceptable bounds. Just what is sufficient empathy and how to determine the fixed bounds on a particular relationship will be determined through upcoming studies with patients, focus groups, and experts.

2.1 A Componential Representation of Shame

Nijhof [13] explicitly described Parkinson's disease as a "problem of shame". In his interviews with Parkinson's patients, he consistently found patients experienced shame after violating various social conventions publicly. The social rules the patients violated varied in their frequency and in their contribution to the intensity of shame experienced by the patients. Further, the magnitude of shame with respect to a rule violation varied based on the public or private nature of violation. The magnitude of shame also depends on an individual's "proneness" to shame [3]. Therefore, it is important to consider the intensity of experienced shame as a composite construct where different components (types of violations) have different weight, and the magnitude a certain component or violation contributes can also vary depending on the individual and the circumstance.

The Components of Shame

In the psychology literature, shame is often decomposed into two independent components [3, 6, 10]. These independent components take different names: internal/external shame [10], defensive/unworthiness shame [5], and negative-self-evaluation/withdrawal shame [3]. Internal shame, which corresponds with defensive and negative-self-evaluation (NSE) shame, is experienced when there are discrepancies between an ideal self, the self that is dictated by personal values, and the public self. External shame, corresponding to withdrawal and unworthiness shame, is experienced when it is those external to the flawed self that present the self as flawed [10]; causing the shamed person to hide/withdraw from the situation [3, 6].

The two components of shame (internal and external) identified above are reminiscent of the two types of stigma, enacted stigma and internal stigma, identified by Rao et al. [16]. With stigma, however, rather than viewing these types as independent components, they view them more as stages in a process. In stigma, individuals experience discrimination in the enacted stigma stage. After recognition of this stigma, the person will seek confirmation of the stereotype and internalize the stereotype. Shame does not require discrimination from an external source [9]. For example, a Parkinson's patient sorting his medication might become confused and might require assistance from an in-home caregiver. This episode might induce internal shame in the patient even though there has been no direct stigmatization. It is important for a caregiver to have a sufficient empathetic response to expressions of internal shame; otherwise, the patient could view a lack of response as abandonment, which will induce additional external shame in the patient [26].

This analysis has transformed shame into a composite of internal and external shame. Retzinger [17] defined six different categories ("direct indication", "abandonment/ separation/ isolation", "ridicule", "inadequate", "discomfort", and "confused/ indifferent") of words that not only frequently appear in the "context of shame" but also help to define circumstances where shame arises. Three of the categories ("discomfort", "abandonment/ separation/ isolation", and "ridicule") fit well under external shame. A person may feel outside of a social network because of people gawking at the symptoms related to his illness or other indirect indicators.

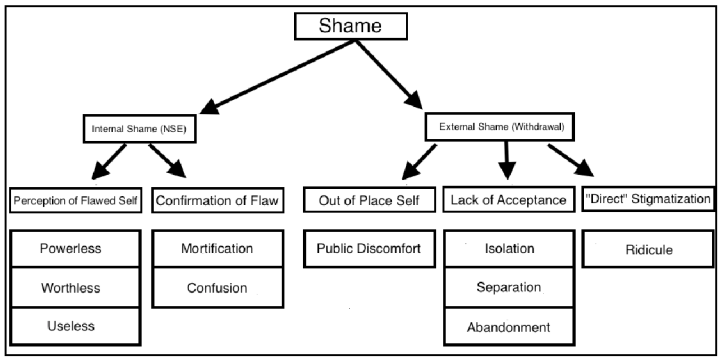

Fig. 1. The decomposition of shame into components. The language that elucidates the lowest level components is taken directly from Retzinger's [17] content analysis.

This separation induces shame because it identifies the self as not "fitting in". The magnitude of external shame experienced by a person can also increase when the symptoms or the illness cause others to "abandon" or "isolate" the sufferer. This is perhaps a more direct indictment, i.e., showing one does not belong. Finally, there is perhaps the most damaging component of external shame, the most direct means by which a flaw costs social worth - "ridicule" by others.

Within internal shame, there are two components ("inadequate" and "confused/indifferent") drawn from the work of Retzinger [17]. First, a person believes that he is flawed and recognizes the potential damage the flaws could have on his social worth/value. Second, the flaw is confirmed in a public setting where the person is unable to function appropriately or fails at a task that he feels marks him as an "undesirable". Note that the sixth category introduced by Retzinger [17] ("direction indication" of shame) decomposed nicely into "ridicule" in external shame and "confusion/indifferent" in internal shame. When one is ridiculed, it is a direct affront on his identity by someone external to the self. Similarly, when one is confused, apathetic and unable to function in the manner in which he was able to function, a discrepancy with the idealized self is revealed. See Figure 1 for a decomposition of shame into its constituent components.

2.2 A Componential Representation for the Empathetic Response

An empathetic response is motivated by both emotion and cognition [5, 8]. Davis's [5] four Interpersonal Reactivity Index (IRI) subscales define trait empathy as a multi-dimensional construct. The four defined dimensions are not combined to form a single value for a person's propensity for empathy; instead, they remain independent. This is due to the interdependence of the dimensions in enacting an empathetic response.

Studies comparing empathy in populations of caregivers working with the chronically ill or the dying against "average" adult populations (e.g. [4]) have found that these caregivers will often have significantly greater capacities for empathetic concern and perspective-taking, two dimensions on Davis's IRI. Perspective-taking is

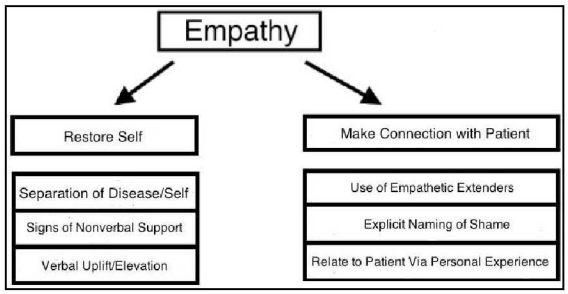

Fig. 2. The decomposition of the empathetic response to shame into components.

a cognitive dimension that allows for the person to "anticipate" the behavior of another person as well as what the needs or wants of the person might be in a certain situation; it allows for appropriate social responses to the individual [5]. Empathetic concern is an emotional dimension that is thought to motivate altruistic action. A person experiences compassion when recognizing suffering or tenderness when recognizing vulnerability [12]. The magnitude of the caregiver's empathetic response is going to depend on convergence between an emotional motivation to help the patient and a cognitive understanding of what the patient needs.

It is logical to model the magnitude of the empathetic response in terms of the components of the interaction where the caregiver attempts to ameliorate the patient's shame. If the caregiver understands the patient's shame and is emotionally motivated to aid the patient, then he will act in a way that mitigates the patient's shame.

Components of an Empathetic Response

When a caregiver is showing the patient that he understands how the patient is feeling, this is not purely a cognitive act but an emotional one as well. The caregiver is deviating from questioning pertinent to the disease (and taking the time) to let the patient tell his "story" [26]. The patient being allowed to speak, and the caregiver providing evidence that he is listening is therapeutic in its own right to the patient [21]. It shows that another person values him; the patient's flaws have not left him unworthy of human contact. To make this connection stronger and more explicit, the caregiver can name the internal state of the patient or can try to relate a personal story to the patient. The caregiver, when sharing a piece of himself with the patient, makes clear the patient is not alone but is experiencing something felt by others.

The caregiver also needs to try to restore the "self" of the patient that has been damaged by the shame. Clearly there is a sympathetic emotional response recognizing the pain of someone who feels unworthy or alone. There is a cognitive aspect to assisting in such a case as well; the caregiver must understand the "self" of the patient has been damaged. The caregiver must show nonverbal support for the damaged self [26], and this support can progress to bolstering the patient's identity through praise for the self (drawing a distinction between the disease and the self). See Figure 2.

2.3 A Componential Representation for Guilt

The notion of computing the magnitude of shame and empathy using components of the patient-caregiver interaction is based on a computational model for the self-conscious moral emotion of guilt. When experiencing guilt, one feels bad for what one has done (finds fault with his actions); this is as opposed to shame where fault is

found with the self [8]. Smits and De Boeck [19] first introduced a componential model for guilt. They found that the probability of a person, i, experiencing guilt in a situation, j, (P_{ij}) could be explained by the "guilt-inducing power" (β_j) of the situation, j, and the person's "threshold" for guilt (θ_i). The logit of the probability of a person experiencing guilt is computed as:

$$\text{logit}(P_{ij}) = a_j(\beta_j - \theta_i) \quad (\mathbf{1})$$

This is just a weighted difference between the "guilt-inducing power" of the situation and the "threshold" of the person for guilt. The "guilt-inducing power" of situation j (β_j) was reliably computed as a weighted sum over the "guilt-inducing power" of just three situational components: "norm violation", "worrying", and "restitution". This is shown in Equation 2. In this equation, σ_k is the weight of the situation component, k, β_{jk} is the guilt-inducing power of component k, and τ is a constant.

$$\beta_j = \sum_{k=1}^{K} \sigma_k \beta_{jk} + \tau \quad (\mathbf{2})$$

Our laboratory has already successfully applied a simplified version of this model for the purposes of restricting weapons systems in a lethal autonomous robotic agent [2]. Equation 3 shows the magnitude of guilt accrued for a specific target, j. Four components were used to compute the guilt for a single target. The parameters of the equation are defined the same as in the above equations.

$$Guilt_j = a_j(\sum_{k=1}^{K} \sigma_k \beta_{jk} + \tau - \theta_i) \quad (\mathbf{3})$$

A similar model to Equation 3 will be used for the accrual of shame and empathy across the patient-caregiver interaction.

3 Overview of Framework Designed to Uphold Patient Dignity

The overview of the framework designed to uphold Parkinson's patient dignity is shown in Figure 3. This framework's core piece, the Emotional Models component, is responsible for computing the magnitude of the patient's experienced shame and the caregiver's expressed empathy in each "empathetic opportunity" [21]. Explicitly, "empathetic opportunities" [21] are single exchanges between the patient and caregiver where the patient experiences shame and the caregiver has the opportunity to respond empathetically. It can also be the case where the caregiver stigmatizes the patient directly (in which case there is no empathetic response). The reason the shame and empathy values are only computed during "empathetic opportunities" is that outside of this context the patient may not believe a caregiver's empathetic response because it may come off as hackneyed [26]. Input into this component of the model is the caregiver's threshold for empathy and the patient's threshold for shame, the weights for the shame and empathy situation components, and the constants for the patient shame and caregiver empathy equations. These are set values shown in

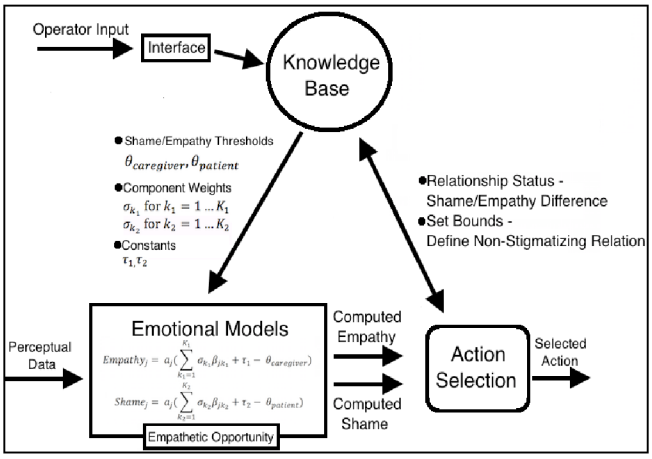

Fig. 3. The framework designed to uphold patient dignity in stigmatizing patient-caregiver interactions.

Equation 3. These values can be determined by experts with the aid of short personality/trait measures, which are common in non-emergent and non-urgent clinical situations, and stored in the Knowledge Base. In the Emotional Models component, the magnitude of shame shown by the patient and empathy expressed by the caregiver in this particular "empathetic opportunity" are computed using these set values and the responses of the components described above.

Takahashi et al. [22] show how, when Parkinson's patients are discussing frustrating activities (a discussion that has a high likelihood of inducing shame), they tend to use more negative language while there is no significant difference in their nonverbal behavior due to the expressive mask. It is logical to assess shame based on the verbal content of what is said by the patient during the interaction. In parallel with this work, our colleagues at Tufts University are developing a speech recognition system specifically designed for Parkinson's patients. This system is expected to be able to reliably recover "keywords" from the patient.

Gottschalk [7] claims that the "magnitude" of a "psychological state" is proportional to the "frequency of occurrence" of words associated with that state, the degree to which the words fall in that state, and the degree to which the words refer to the self. Retzinger [17] provides a content analysis that identifies words indicative of our different component categories. If it is assumed that the patient is discussing his condition with the caregiver, the language will largely refer to the self. Therefore, the magnitude of the experienced shame contributed by each component during a given patient response is proportional to the frequency with which the patient uses the words in these categories.

It is important to have alternative means to confirm the responses of these components. Further, the caregiver response has the opportunity to induce shame in the patient. Therefore, it is important to consider alternative cues that can contribute to the components' responses recognizing the limited availability of nonverbal cues.

The *Out of Place Self* component is defined by words such as "antsy", "nervous", and "tense" [17]. The patient is fearful and wants to withdraw from the situation. The patient will likely avert his eyes [8] as a means of trying to withdraw. Therefore, a

gaze tracker is used to assess the response of this component with the magnitude of the response proportional to fraction of the time the patient averted his gaze during the single exchange. This component is going to have a response when the patient is anxious or fearful. Fear was reliably differentiated from sadness, anger, surprise, frustration, and amusement using galvanic skin response, skin temperature and heart rate signals in healthy populations [11]. Components of heart rate variability correlate with emotional intensity [25]. The response of this component is assessed by identifying fear and assessing the magnitude based on how the heart rate varied.

Terms such as "alienated", "deserted" or "ostracized" [17] define the *Lack of Acceptance* component. Patients may feel that, when the doctor has "abandoned" them or is not actively supporting them, it is because they are dying or a lost cause [26]. This is going to stress the patient. When Parkinson's patients are stressed, it causes a worsening of their symptoms [15]. The baseline tremor for the patient is measured just before the interaction, and significant worsening bolsters the magnitude of this component's response. This component should also increase when the patient expresses shame (i.e. any shame component is nonzero) and there is no empathetic response (the empathetic response components are zero) [26].

Ridicule is likely to inspire a measure of anger in the patient [26]. As mentioned above, anger is recognized in healthy populations, in controlled settings with easily obtainable physiological signals [11]. The *"Direct" Stigmatization* component response is computed by recognizing an amount of anger arising in the patient. This component should also increase when the caregiver directly stigmatizes the patient. Speech recognition for the caregiver should be better than the speech recognition for the patient, which would allow for more complete sentences/phrases to be recovered. The caregiver stigmatizes the patient when a word of negative valence and high intensity qualifies a proper noun or pronoun corresponding to the patient.

When the patient perceives himself to be "worthless" or "helpless" [17], as in the *Perception of Flawed Self* component, the patient is profoundly sad. Sadness is assessed with the basic physiological signals as noted above [11].

Finally, the *Confirmation of Flaw* component response is going to increase when the patient is "mortified" because of his inability to complete a common task, or he has "muddled" thoughts such that he is unable or unwilling to interact well with the caregiver [17]. The patient's inability to perform relative to his previous self is liable to leave the patient frustrated. Frustration is differentiated based on simple physiological signals [11]. One could also monitor specific parts of the interaction where a patient may fail, such as responding to orientation questions. When a failure occurs, the response of the component increases.

When the caregiver is trying to ameliorate the patient's concerns, it is essential that the caregiver show compassion for the patient [26]. This is required for a low magnitude response in the *Restore Self* component. A high magnitude response or a fully empathetic response would not only nonverbally support the patient (showing the flawed self is valued), but it would mitigate the shame of the patient by praising the self (showing that the negative outcomes for the patient are related to his condition rather than the self).

A classifier indicating the intensity of the caregiver's compassion will be constructed. The features used by the classifier could include the caregiver's facial expression, voice prosody, gaze, posture, and orientation toward the patient during the

empathetic opportunity. The caregiver can be said to praise the patient if the patient is referred to with a positive adjective/adjectival clause.

At a basic level, making a connection with a patient requires the caregiver to respond appropriately and directly to what the patient has been saying. This is done through the use of "empathetic extenders" [21], which take standard forms such as "How sad", "How awful" or "It's very hard" [26]. These types of responses are a low magnitude empathetic response. High magnitude responses show the patient that he is understood. This is most commonly done by explicitly naming the emotion using phrases such as "You seem upset" [26]. These types of responses are identified using paraphrase recognition to assign a magnitude to the *Make Connection With Patient* component.

After the global magnitudes of shame and empathy have been computed, their difference is added to the running difference between the patient shame and caregiver empathy. If the difference between patient shame and caregiver empathy falls outside of set bounds, then the robotic agent must try to unobtrusively guide the relationship [1] such that there is congruence between what the patient is feeling and what the caregiver understands the patient to be feeling (indicated by the caregiver having an empathetic response that matches the magnitude of patient shame).

4 Conclusions and Future Work

This paper introduced componential representations of shame and empathy, the basis for a computational model that is tasked with upholding the dignity of a Parkinson's disease patient in a stigmatizing relationship with his caregiver. These representations are based in the psychology literature. Forthcoming human-robot interaction studies will elucidate the weights, thresholds, and constants for the evaluation of the global shame and empathy magnitudes. There has been a paucity of studies on how a robotic agent can guide interactions between a human dyad (an exception being [9]). In addition to finding project specific guidelines when computing values for shame and empathy, our work will focus on how to best elicit empathy from the caregiver when the patient is in jeopardy of suffering indignity.

Acknowledgments. This work is supported by the NSF under Grant #IIS 1317214 in collaboration with Linda Tickle-Degnen and Matthias Scheutz at Tufts University.

References

1. Arkin, R.C.: Ameliorating Patient-Caregiver Stigma in Early-Stage Parkinson's Disease using Robot co-Mediators, Proc. AISB 50 Symposium on Machine Ethics in the Context of Medical and Health Care Agents, London, UK, (April 2014)
2. Arkin, R. C., & Ulam, P.: An ethical adaptor: Behavioral modification derived from moral emotions. In International Symposium on Computational Intelligence in Robotics and Automation (CIRA), 2009 IEEE (pp. 381-387). IEEE, (December 2009)
3. Cohen, T. R., Wolf, S. T., Panter, A. T., Insko, C. A.: Introducing the GASP scale: a new measure of guilt and shame proneness. Person. & Social Psych., 100(5):947-966 (2011)
4. Claxton-Oldfield, S., Banzen, Y.: Personality characteristics of hospice palliative care volunteers: the ''big five''and empathy. American Journal of Hospice and Palliative Medicine, 27(6), 407-412 (2010)

5. Davis, M. H.: Measuring individual differences in empathy: Evidence for a multi-dimensional approach. Journal of personality and social psychology, 44(1), 113 (1983)
6. Giner-Sorolla, R.: 5 Shame and Guilt. In Judging passions: Moral emotions in persons and groups, Psychology Press, (2013)
7. Gottschalk, L. A.: Some psychoanalytic research into the communication of meaning through language: the quality and magnitude of psychological states*. British Journal of Medical Psychology, 44(2), 131-147 (1971)
8. Haidt, J.: The moral emotions. Handbook of affective sciences, 11, 852-870 (2003)
9. Hoffman, G., Zuckerman, O., Hirschberger, G., Luria, M., Shani-Sherman, T.: Design and Evaluation of a Peripheral Robotic Conversation Companion. Proceedings of the Tenth Annual ACM/IEEE International Conference on Human-Robot Interaction, ACM, (2015)
10. Lee, D. A., Scragg, P., Turner, S.: The role of shame and guilt in traumatic events: A clinical model of shame‐based and guilt‐based PTSD. British Journal of Medical Psychology, 74(4), 451-466 (2001)
11. Nasoz, F., Alvarez, K., Lisetti, C. L., Finkelstein, N. Emotion recognition from physiological signals using wireless sensors for presence technologies. *Cognition, Technology & Work*, *6*(1), 4-14 (2004)
12. Niezink, L. W., Siero, F. W., Dijkstra, P., Buunk, A. P., Barelds, D. P.: Empathic concern: Distinguishing between tenderness and sympathy. *Motiv. & emotion*, *36*(4)544-549 (2012)
13. Nijhof, G.: Parkinson's disease as a problem of shame in public appearance. Sociology of Health & Illness, 17(2), 193-205 (1995)
14. Nordenfelt, L.: Dignity of the elderly: an introduction. Medicine, Health Care and Philosophy, 6(2), 99-101 (2003)
15. Oertel, W. H., Ellgring, H. Parkinson's disease—medical education and psychosocial aspects. Patient education and counseling, *26*(1), 71-79, (1995)
16. Rao, D., Choi, S. W., Victorson, D., Bode, R., Peterman, A., Heinemann, A., Cella, D.: Measuring stigma across neurological conditions: the development of the stigma scale for chronic illness (SSCI). Quality of life research, 18(5), 585-595 (2009)
17. Retzinger, S. M.: Violent emotions: Shame and rage in marital quarrels. Sage, (1991)
18. Sabini, J., Garvey, B., Hall, A. L.: Shame and embarrassment revisited. Personality and Social Psychology Bulletin, 27(1), 104-117, (2001)
19. Smits, D. J., De Boeck, P.: A componential IRT model for guilt. Multivariate Behavioral Research, 38(2), 161-188 (2003)
20. Steinbock, A. J.: Shame. In Moral emotions: Reclaiming the evidence of the heart, Northwestern University Press, (2014)
21. Suchman, A. L., Markakis, K., Beckman, H. B., & Frankel, R.: A model of empathic communication in the medical interview. Jama, 277(8), 678-682 (1997)
22. Takahashi, K., Tickle-Degnen, L., Coster, W. J., Latham, N. K.: Expressive behavior in Parkinson's disease as a function of interview context. The American journal of occupational therapy: official publication of the American Occupational Therapy Association, 64(3), 484-495 (2010)
23. Tickle-Degnen, L.: Chapter 14: Therapeutic rapport. In M. V. Radomsky & C. A. Trombly Latham (eds.), Occupational Therapy for Physical Dysfunction (7th ed), Baltimore: Lippincott William & Wilkins, 412-427 (2014)
24. Tickle-Degnen, L., Zebrowitz, L. A., Ma, H. I.: Culture, gender and health care stigma: Practitioners' response to facial masking experienced by people with Parkinson's disease. Social Science & Medicine, 73 (1), 95-102 (2011)
25. Uy, C. C., Jeffrey, I. A., Wilson, M., Aluru, V., Madan, A., Lu, Y., Raghavan, P. Autonomic Mechanisms of Emotional Reactivity and Regulation. Psychology, 4(08), 669-675 (2013)
26. Zinn, W.: The empathic physician. Archives of Internal Medicine, 153(3), 306-312 (1993)