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Open Problems in Medical Pedagogy

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It has recently been noticed that problems of specific specialisations in the area of special education overlap or exceed the constraints of a given sub-discipline. The article addresses the issues related to outlining the major problems that may be encountered in the area of medical pedagogy, and which are crucial for the lives of people suffering from a chronic illness in various areas of their functioning. These issues include body traits and their importance in building identity in the situation of experiencing a chronic illness; coping with loss in a situation of a chronic illness; adjustment in reciprocal contacts with a person with a chronic illness and participation in social exchange.

KEY WORDS: medical pedagogy, chronic illness, body, identity, sense of control, resource, loss, coping, adjustment in contact, social exchange

The teaching of persons with a chronic illness was traditionally combined with the teaching of persons with motor disabilities, and these activities were called medical pedagogy. Nowadays, these two approaches are often separated, primarily on account of the fact that problems encountered by chronically ill persons have a different nature¹.

¹ A. Zawisław, *Wybrane zagadnienia z pedagogiki specjalnej*, Oficyna Wydawnicza Impuls, Kraków 2009.

The task of medical pedagogy is primarily educational and maintenance support for children, youth and adults suffering from a chronic illness, incorporated into the treatment process.

The teaching of chronically ill persons is often related to such issues as: impact of the chronic illness on the individual's functioning in various areas of life, including the use of educational activities and maintenance activities as a therapeutic factor; it determines and adjusts educational activities to the physical and stress capacity of chronically ill persons, contributes to the organisation of the educational and maintenance process at the place of stay of the chronically ill person and ensures support for the family of a chronically ill person.

It is worth emphasising that medical pedagogy, on account of its' area of interest, exceeds the strict range of special education and is related to the issues pertaining to the old age.

In the area of medical pedagogy, it is possible to separate issues that require in-depth examination and research exploration. Thus, the primary objective of the paper is to provide new perspectives on issues in this respect. We would like to delve into four problems which may be divided into two categories. Two of them refer directly to the person suffering from a chronic illness, whereas two others refer to his/ her interactions with other people.

The first group includes problems pertaining to:

- (1) body traits: their significance in building identity in a situation of a chronic illness experience;
- (2) coping with loss during a chronic illness.

The second group of problems encompasses:

- (1) adjustment in reciprocal contact with a chronically ill person;
- (2) participation of chronically ill persons in social exchange.

Body Traits: Their Significance in Building Identity in a Situation of a Chronic Illness Experience

The body is a place where we have the pleasure or the misfortune of residing. It is the source of a good frame of mind and pleasure, but it is also the object of illnesses and stresses. It is not only

a physical object that every man possesses. It constitutes a scheme of operation and a source of practices, whose active involvement in daily interactions is necessary to preserve a consistent self-sense².

Every man functions in the world in the "corporeal" manner. A human being cannot function without a body. We function in such reality and we experience it in a manner that is enabled by our bodies. Body is an individual's property; it offers the individual a possibility of self-control, feeling of corporeal consistency, but also the experience of its' absence. Man also has a certain possibility of shaping own body, yet this is related to the fact that man assumes responsibility for the "effect"³.

The sense of corporeal identity is a process of accumulating individual experiences related to own body. Inability to name own feelings, experiences and needs that originate from the body causes numerous stresses and results in the loss of bearings in the world of personal experience. The ability of modulating the power of own experiences and knowledge about the causes of their origin contribute to self-control. Erving Goffman claims that everybody who experienced moments of confrontation with emotions that are impossible to bear, in particular when their emergence was unexpected, knows the feeling of alienation from such experiences. People are also aware of the sense of corporeal consistency and the experience of its' absence. The body gains special significance in the case of persons whose bodies are "attacked and affected" by an illness. Symbolic interactions between the feeling of normalcy in reference to the physical appearance or functions of individual organs of the body may be related to the loss of significant attributes and lead to stigmatisation, consistent with the approach presented by Erving Goffman.

In the light of the assumptions of symbolic interactionism and studies of Katarzyna Piątek, it is possible to define body control:

² A. Giddens, *Nowoczesność i tożsamość „Ja” i społeczeństwo w epoce późnej nowoczesności*, PWN, Warsaw 2001, p. 137.

³ Z. Bauman, *Ciało i przemoc w obliczu ponowoczesności*, Wydawnictwo UMK, Toruń 1995, p. 192.

“body control and management depend on the relatively autonomous human subject”⁴. In illness, the feeling of loss of control over own body is one of its’ most important consequences. Social identification of an ill person exerts impact via changes in the body (decimated body, body deprived of certain inner invisible organs) or a body with visible changes, stigmatised by an illness and disability or mutilated as a result of the applied therapy. This may be accompanied by the sense of embarrassment, self-consciousness, mortification on account of the stigma of illness on the body.

The body acquires the status of a resource which can be managed; it contributes to creating a version of “own I”⁵. Meanings ascribed to the body are designated by the conventional form of non-verbal communication over which the individual has no control, yet which influences the categorisation of own self and others. People are being taught from early years how to present their bodies in the social space. A body that does not meet certain “standards”, a body over which one has no control and the behaviour of which is not clear to interpret for the environment is subject to exclusion⁶. The significance that man ascribes to own body is, to a great extent, conditioned by knowing the idiomatics of the body; a chronically ill person not always has direct control over it⁷.

Referring to the body concept of Erving Goffman, it has to be emphasised that an individual that undertakes activities within social borders has certain restrictions that influence the individual’s autonomy. In her studies on women with motor disabilities, Katarzyna Piątek (2012) presents them as persons having potentially the only impact on their corporeality, yet who are dependent on social control. This is related to the stance of Chris Schilling (2010), who claims that a human body is characterised by a dual location:

⁴ K. Piątek, *Ciało nadzorowane. Strategie kontroli ciała podejmowane przez kobiety z niepełnosprawnością fizyczną*, [in:] *Fenomeny kontroli ciała*, ed. E. Banaszek, P. Czajkowski, R. Florkowski, Diffin, Warsaw 2012, p. 168.

⁵ C. Schilling, *Socjologia ciała*, PWN, Warsaw 2010.

⁶ Ibidem.

⁷ K. Piątek, op. cit., pp. 168–169.

individual (as the property of every individual) and social (defined and controlled by the society)⁸.

Thus, the body plays a vital role in the relations between the identity of an individual and the social identity. Social value attributed to the body is accepted by the individual and has its' share in the formation of "I" and the feeling of self-esteem. The feeling of social identity built through the body and the concept of the image of own body means the control of own life situation via efficiency of undertaken activities, which are aimed at maintaining or verifying the hitherto social relations⁹.

Body management plays a crucial role in maintaining social relations (joining the social space by a chronically ill person) and results in the fact that such person enters the world of meanings and languages of other people, functioning in a slightly different reality. In such a situation, the body becomes an "intermediary" between the personal identity and the social identity.

The discussion above implies problems in the area of medical pedagogy. First of all: in which degree do chronically ill persons perceive their bodies as an element of causality and have control over it, as well as which control strategies do they use with respect to their bodies? Secondly: how do chronically ill persons experience control within their body and in which degree do their decisions pertaining to the body depend on social control?

Coping with Loss During Chronic Illness

In the context of issues discussed here, the problem of loss is of fundamental significance. A person suffering from a chronic illness, in order to function in a satisfactory manner based on the possessed resources, has to be able to cope with the feeling of loss.

⁸ C. Schilling, *op. cit.*

⁹ M.P. Kelly, D. Field, *Medical sociology, chronic illness and the body, "Sociology of health and illness"*, 18, 1996, pp. 241-257.

Loss is “what is no longer possessed; also: the fact that one no longer owns something”¹⁰. The feeling of loss is an emotional state emerging in reaction to an inner conviction about “absence” of an object, a person, possibilities. This emotion is unpleasant and it is used to make one aware of the need, which has to be satisfied with different methods than so far (before the loss)¹¹. Different types of experienced losses may be listed here.

A loss may be perceived as a situation when something is missing; there is less of it within one’s reach. It may also be interpreted as a situation of deprivation, a deficit of something that was available or what is available to others, but not to a given person. A loss may also be experienced as absence, disappearance of somebody or something significant for the individual. Coping with the feeling of loss is related not only to its’ object (what has been lost), but also the mode of experiencing and interpreting it and its’ significance.

The situation of loss of a person (as a result of death) entails anxiety that is difficult to cope with, despair, feeling of helplessness, risk of losing the sense and the purpose of life. It is perceived as uncompensated loss related to the feeling of disappearance, absence of a significant person. Reaction to it acquires the form of grieving. The characteristic phenomena in this situation are reactions of escape and return to the problem, yet with a lesser intensity of emotions¹².

In psychology, the loss of a person is identified with grieving. Grieving is a process, as emphasised by Z. Freud. Erich Lindemann was the first to talk about doing “grief work” and emphasised its’ variability and necessity of utilising physical and mental energy to be able to cope with such process. Grieving is the “working” of feel-

¹⁰ Słownik Języka Polskiego ed. L. Drabik, PWN, Warsaw 2006.

¹¹ G. Sędek, *Jak ludzie radzą sobie z sytuacjami, na które nie ma rady?*, [in:] *Złudzenia, które pozwalają żyć. szkice z psychologii społecznej*, ed. M. Kofta, T. Szustrowa, PWN, Warsaw 1991.

¹² G. Sędek, *Jak ludzie radzą sobie z sytuacjami, na które nie ma rady?*, [in:] *Złudzenia, które pozwalają żyć. Szkice z psychologii społecznej*, ed. M. Kofta, T. Szustrowa, PWN, Warsaw 1991, pp. 289–319.

ings, stances and relations with a person who is gone¹³. Its' stages are have different names and are diversely interpreted by various authors. In this place, it is worth paying attention to the model of Franklin C. Shontz, important for clarifying the reaction to the loss of a close person. The model assumes that the first reaction to death is a shock. Persons in a state of shock retain amazing lucidity of thinking and significant efficiency in undertaken actions. The "drama" does not reach them; they live separated from the reality. They encounter the helplessness, disorganisation and despondence only after a while and it is only then that they are confronted with the pain; this significantly aggravates cognitive functioning. A constant feeling of loss tends to be tiring. In relation to this, people try not to think about a difficult event, which leads to a situation where there is suppression and a temporary improvement of spirits. At the moment when difficult emotions emerge, some people find it difficult to cope with them and the consequence is the appearance of the withdrawal stage.¹⁴ According to Franklin C. Shontz, the variability of ensuing stages has a good impact on a given person and in the course of time allows for adjustment to the new situation. Along with the passage of time, difficult emotions appear more and more rarely and, in effect, new goals may be determined. Moving between the stages of confrontation and withdrawal does not have the accommodative nature. It is a necessary condition of development¹⁵.

Another type of experiencing loss may have the character of **a loss in the context of loss of an object**. In this case, there are various modes of interpreting such situation. The mode of interpreting it depends on the scale of loss and the significance that the lost objects had for one's well-being. When the means that allow for the

¹³ A. Ostrowska, *Śmierć w doświadczeniu jednostki i społeczeństwa*, Wydawnictwo IFIS PAN, Warsaw 1997.

¹⁴ Ibidem, pp. 289-319.

¹⁵ B. Dobrzańska-Socha, *Pomoc psychologiczna w sytuacji straty*, [in:] *Zmagając się z chorobą nowotworową. Psychologia współczesna wobec pacjentów onkologicznych*, D. Kubacka-Jasiecka, W. Łosiak ed., Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 1999, pp. 289-340.

satisfaction of basic life needs are lost, one may sense their disappearance, non-existence and experience trauma. With respect to other minor scale cases, one may experience deprivation, which is combined with the irreversibility of loss or one may perceive certain loss as a deficiency, reduction of certain resources. Coping with such situation has a primarily pragmatic nature, material and instrumental support allowing for a decrease in the costs of deficiency. One of the forms of coping with this type of loss is transformation of this experience into a subject that forms a basis for contacts with others (story about ...). It may be analysed in the context of what a specific situation has given the person who experiences it, what it has taught such person, what kind of experiences may be drawn from such situation and what may be done in reference to such loss (starting the strategy of coping with the loss and minimising its' costs). This type of loss has the nature of being experienced "from the outside" as a result of personal situation, which a given person could not have avoided.

A chronic illness, both at the beginning and in the course of its' progress, is related to the fact that the person is experiencing **loss within oneself**: the person is deprived of the skills, the capacity with respect to body functions, the autonomy, the self-fulfilment and the ability to perform social roles. The experience of loss may be very serious and may refer to important aspects of body functioning, even leading to its' complete incapacity.

Loss within oneself in a situation of a chronic illness is the most painful loss. It is due to the fact that the individual is aware of the difficulties of substituting such loss. Loss in the dimension of loss of health results in the fact that an individual experiences the decrease of the feeling of own potential.

The process of becoming reconciled with the losses in life and the feeling of development within the limits designated by an illness is never easy and painless for man. The feeling of loss is often accompanied by the feeling of failure, which results in the fact that a loss is additionally assessed and the entire burden seems to be unbearable. Losses sustained as a result of a chronic illness include

losses that are hard to become reconcile with. According to Silvia Bonino "heavy losses are like wounds, which are a part of ourselves; we have to learn to live with them; in their existence, we have to find a reason for inner development, in spite of the fact that such wounds may sometimes open, hurt and bleed"¹⁶. The process of loss within oneself is not identical with the experience of grieving. It may be treated as grieving, but a given person has to work the loss.

Loss within oneself also acquires another nature when one is dealing with acquired and not inborn illness. In such case, the person compares what was available and possible before the illness in various areas of life. Along with the appearance of illness, a person loses his/ her prior opportunities and in case of a progressing illness, the person is also aware of the future, subsequent losses.

An ill person experiences loss in an irreversible manner. When discussing the phenomenon of loss related to the illness, it is necessary to draw attention to the fact that acceptance of an illness may take place after coping with the loss within oneself. In relation to this, the following questions appear: in which context does the loss within oneself have a mobilising character and in which context does it become demobilising, with special attention given to the dynamics of the entire illness process? Which strategies are used by chronically ill persons to cope, with special attention given to the dynamics of a given illness process? May a loss (and in which degree) experienced internally by a chronically ill person become a subject matter in contacts with other persons, with whom and for which purpose?

Adjustment in Reciprocal Contacts with a Chronically Ill Person

The issue that our body delimits the reality in which we function was emphasised at the beginning of discussing the selected

¹⁶ S. Bonino, *Tysiące nici mnie tu wiążę*, Wydawnictwo APS, Warsaw 2008, p. 66.

problems in the area of medical pedagogy. In relation to this, people may experience a certain dissonance between own awareness pertaining to the reality and the possibilities of functioning with the body in such reality (or with respect to the information from the outside – we see others or own experience from before the illness).

Thus, it may be claimed that a chronically ill person has to cope with a situation of dissonance. If an individual rejects the dissonance, this may cause certain forms of rebellion, passive or active resistance, struggle with the adversities or with the environment. Reflective “work” on the dissonance allows for attempting to fit in specific situations and may form an important factor in the process of adjustment.

The phenomenon of adjustment occurs in two forms: (1) adjustment of activities to external conditions (items created by man acquire ergonomic shapes adjusted to his/ her motor activities); (2) in interactions, consisting in the awareness of signals and communications deriving from persons with whom specific activities are shared¹⁷.

The problem of adjustment also occurs in verbal communication (in the area of partner communication). Specific behaviour is often required from a person with whom one enters into contacts. People even demand that such person is able to function within a designated outline and stereotypically fits into the framework created for a specific situation. For example, when our interlocutor behaves in a non-standard manner on account of his/ her characteristics, we try to “adjust” to him/ her.

Taking care of the satisfaction of own needs in mutual contacts is greatly important in the communication perspective. In the relations of both partners with varied communication skills, each of them should always preserve their individuality and be aware of their needs and reasons. However, this may be hindered when, on

¹⁷ H.R. Schaffer, *Wzajemność kontroli we wczesnym dzieciństwie*, [in:] *Dziecko w świecie ludzi i przedmiotów*, ed. A. Brzezińska and G. Lutomski, Wydawnictwo Zysk i S-ka, Poznań 1994, pp. 130–131.

account of communication according to various linguistic codes, mutual understanding is impeded or one of the parties experiences dependence on the other party. Use of varied vocabulary or display of a different style of holding a conversation may determine the failure of a given situation, without the conscious fault of interlocutors. This happens because each of them communicates according to a well-known scheme, at the same time applying own communication strategies, without taking the interlocutor's perspective into account.

In the literature, adjustment primarily takes place with respect to the analysis of activities of a person taking care of a small child – the younger the child, the more pronounced adjustment is noticed; in case of adults, attention is primarily drawn to problems resulting from lack of adjustment, leading to depersonalisation. This phenomenon is discussed more broadly in the context of total institutions¹⁸. In the relation of caring, adjustment is hidden in the specification of the term of **care**. This term is often treated as the synonym for the term **caring**, yet in her monographic study, Judith Philips tries to nuance these terms by indicating the emotional charge contained in the term care. She presents the following description of the term care: *“a reaching out to something other than self: it is neither self-referring or self-absorbing. Second, care implicitly suggests that it will lead to some type of action.”* Furthermore, the author emphasises that care may be perceived as a holistic term, pervading all relations and human activities¹⁹. By understanding this term in this manner, it is possible to distinguish between caring as activities supporting the accomplishment of other person's needs, which such person cannot satisfy on his/ her own, and care where the emotional context of such activities becomes visible, leading to attention to the well-being of the care-recipient.

¹⁸ E. Tarkowska, *Ludzie w instytucji totalnej. Przypadek domów pomocy społecznej w Polsce*, [in:] *Upośledzenie w społecznym zwierciadle*, ed. A. Gustavsson, E. Zakrzewska-Manterys, Wydawnictwo ŻAK, Warsaw 1997.

¹⁹ J. Phillips, *Troska*, Wydawnictwo SIC!, Warsaw 2009, pp. 24–25.

It may be noticed that in such understanding of the term care, the phenomenon of adjustment is emphasised more clearly. It becomes apparent in both meanings: in the first case, pertaining to the relevance of activities and external conditions and, in particular, in the second one, focused on the awareness of signals and communications deriving from a person with whom a given activity is shared. In this place, a very important issue of co-sharing care is revealed; care refers to a supported person. The supporting person shows care when, whilst performing specific support activities, he/ she pays attention to the signals and communications improving or threatening the well-being of the recipient of care/ assistance. The care relationship is, however, co-dependent. The care of the supported person with respect to the person who provides support is also important; it is expressed in various types of behaviour, revealing active co-participation in the co-shared activity.

The analyses above imply specific problems for medical pedagogy: What costs are related to the process of adjustment of activities as part of interactions of persons participating in it? How to define the borders of possibility of adjusting activities as part of interaction which has the nature of assistance? What effects result from lack of adjustment in interaction, in particular in case of a situation when assistance is provided?

Participation of Chronically Ill Persons in Social Exchange

In sociology, social exchange is the process of exchange of goods and services at least between two persons, leading to the establishment of durable acquaintances and setting up supremacy over others²⁰. It is also treated broadly: interaction as an exchange²¹. Exchange is one of the modes in which persons create and solidify

²⁰ P. Blau, *Wymiana społeczna*, [in:] *Socjologia. Lektury*, ed. P. Sztompka, M. Kucia, Wydawnictwo Znak, Kraków 2005.

²¹ G.C. Homans, *The nature of social science*, University Press, New York 1967.

the social organisation. In such approach, the exchange is a very important source of social order for such persons, which is created as an unplanned result of acts of exchange among members of the society. The exchange becomes a certain voluntary transaction, consisting in the transfer of various types of goods between two or more individuals, from which everybody derives benefits. In this case, the transferred goods have material nature, as well as immaterial one (social recognition, prestige and value of what is attributed to a given group)²². For Georg C. Homans, social interaction takes place when "activity of one person is rewarded or punished by another person"²³. In such approach, participation in a social interaction is related to the conviction that goods valued by one person or needed by such person are owned by other people who can reward him/ her with the use of them. To encourage them to do it, it is necessary to give them something in the form of goods or services. This is how the social network is created.

The core of the functioning of the social network is social exchange. Social exchange is a contract that builds durability. As far as social exchange is concerned, the principle of reciprocation applies with respect to it²⁴. It may be noted that exchange and the principle of reciprocation applicable as part of it are the mechanism of **building a social network**. The more a person participates in the exchange, the more "rooted" he/ she is in the social network.

In this context, it is necessary to refer to the concept of social support, which is the consequence of a man's affiliation to the social network²⁵. Social support may be described as a type of social interaction which was undertaken by one or several participants of a problematic, difficult, stressful or critical situation. In the course of

²² B. Szacka, *Wprowadzenia do socjologii*, Wydawnictwo Oficyna Naukowa, Warsaw 2003, p. 124.

²³ Ibidem, p. 124.

²⁴ C. Lévi-Strauss, *Zasada wzajemności*, [in:] M. Kempny, J. Szmatka ed., *Współczesne teorie wymiany społecznej. Zbiór tekstów*, PWN, Warsaw 1992.

²⁵ J. Pommersbach, *Wsparcie społeczne a choroba*, „Przegląd Psychologiczny”, 1988, 31, 2, pp. 503–525.

such interaction, transfer or exchange of emotions, information, instruments of activities and material goods takes place. The exchange may be unilateral or bilateral, whereas its' direction may be fixed or variable. It is worth emphasising that in a specific layout of interaction, it is possible to distinguish a supporting person, a person looking for support or a person receiving support. For the social exchange to be efficient, liability between the type and the range of provided support is of great importance, as well as the needs of the recipient – a chronically ill person²⁶.

Functional features of support constitute a basis for its' division into perceived support and received support. Perceived support primarily results from knowledge and convictions of an ill person with respect to the fact where and from whom assistance may be procured, who can be counted on in a difficult, stressful situation. In this type of support, assessment of beliefs of a given person about availability of the network is made. On the other hand, received support is evaluated objectively or subjectively narrated by the recipient as actually received type and amount of support. Perceived support and received support depend on the context of a difficult situation, as well as needs of chronically ill persons and features of social networks available and used in specific situations. Support interactions and efficiency of their operation are significantly conditioned by the features of a supported person. They depend on the persons' personal resources, resources of the "I" structure, self-evaluation, self-control, social competence and the person's social position. Taking into account the features of a chronically ill person (supported person), it is necessary to indicate the needs of social support as permanent features. They may be objective, taking into account the age and the social position, impacting independent coping with difficulties or they may form the feature of a dependant personality. Slight intensity of the needs of support and revealing

²⁶ H. Sęk, R. Cieślak, *Wsparcie społeczne – sposoby definiowania, rodzaje i źródła wsparcia, wybrane koncepcje teoretyczne*, [in:] *Wsparcie społeczne, stres i zdrowie*, ed. H. Sęk, R. Cieślak, PWN, Warsaw 2006, p. 18.

them is encountered in persons with a strong desire for autonomy and independence²⁷.

If support is not perceived by a chronically ill person, it is possible to determine that it is more beneficial for the individual. Primarily due to the fact that if a man is aware of the support, it influences his/ her self-esteem. The effect of underestimated self-esteem is revealing specific modes of recovering control over the situation (example: entitlement mentality). Thus, participation in the social exchange is necessary for the ill person to experience well-being primarily in order to feel in control of the situation.

Thus, the key questions appear: how to offer support, including educational support, to chronically ill persons in order to solidify their potential in the social exchange? And: how to offer support to chronically ill persons in order to facilitate their participation in the asymmetrical social exchange?

The problem questions presented as part of the individual areas constitute open issues that require further in-depth exploration due to the fact that they are of key significance for the life of chronically ill persons in various areas of their functioning.

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²⁷ Ibidem, p. 21.

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