

QUALITY OF LIFE OF THE PERSONS WITH INBORN GENDER IDENTITY DISORDER SYNDROME

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ABSTRACT

The paper discusses the issue of quality of life of persons with Inborn Gender Identity Disorder Syndrome (IGIDS). The sociological concept of quality of life is a useful concept to explain many aspects of social activity and social practices implemented by individuals as well as specific social groups and categories. So far, in Poland, there is no comprehensive (in the legal, medical and social sense) solution to the problems of persons with IGIDS [1]. This leads to discrimination and significantly worsens the conditions for their functioning in society. The high frequency of suicidal thoughts and attempts (including frequent self-mutilation) among this social category is the best proof of how uncomfortable life is for people with this congenital disorder and how much difficulty they have to face. Negative social perception only deepens their sense of marginalisation and alienation. Therefore, sociological identification of the real problems of persons with IGIDS becomes very important as regards the attempts to improve this situation.

The purpose of the paper is to consider the research possibilities of getting to know the lifestyles and quality of life of persons with IGIDS. Sociological recognition of these issues may be useful from the point of view of the impact on raising public awareness of this developmental disorder. It can also contribute to a better understanding of the problems of those affected by the public. Raising awareness of this problem seems to be an antidote to negative prejudices and marginalisation of persons with IGIDS that are found in society.

***Keywords:** lifestyle, biographical method, autobiographical interview, life course (trajectory), qualitative and quantitative methods*

INTRODUCTION

The biographical method is a well-established and recognized sociological method of studying the course of life of individuals. The precursors of biography research on the basis of personal documents were Florian Znaniecki and William Thomas, and the research using this method was continued and developed by Józef Chałasiński and Jan Szczepański [2]. This method of research primarily covers written communications that individuals create and leave, mainly for private use. These are diaries, journals, family chronicles, other notes and chronological entries. Nowadays, this role is also fulfilled by regular Internet blogs, access to which is almost universal and immediate.

Obtaining life course material can also come from research deliberately launched by social researchers. This is the nature of announced competitions for memories of specific stages of life or descriptions of individual fates related to important historical events. Finally, data on individual biographies can be obtained through an autobiographical interview. It should be stressed, however, that not every in-depth interview meets the conditions for an autobiographical interview [3]. Moreover, such a study is extremely time-consuming and labour-intensive. Collecting data (transcript of a conversation or its recording) during a one-off interview takes a relatively long time and obtaining more material must also involve a greater number of researchers. In addition, the processing of the collected material requires a great deal of effort and resources. A small number of interviews does not allow for generalising the results and transferring them to a wider category of respondents. However, the raw material obtained in this way has a high cognitive value; it contains not only information about the respondent and his or her way of seeing things, but also reflects his or her personal characteristics (the way of speaking, language, cultural competencies). It is a kind of qualitative research. Because of these limitations, researchers sometimes resort to the use of such research on a very small scale. The material obtained is then used as an illustration of a large-scale survey (quantitative method) or is confined to a small research sample and limited inference to investigated studies only.

It seems, however, that despite these methodological conditions, the use of biographical research (knowledge of life course) is a useful paradigm when it comes to investigating the fate of persons with IGIDS. It is pointed out that both the symptoms of this disorder, their intensity and the way they occur, as well as the ways of coping with the dissonance diagnosed in individuals are highly individualised. Individual cases, although they have some common features, can be very different from each other. This requires not only an individual therapeutic approach, but also specific (individual) research in social sciences. Individual biographies of persons with IGIDS and the course (trajectory) of their lives may be considered as individual cases or refer to significant moments on the path to sex reconciliation. Such turning points can be: the very recognition of the disorder by the person concerned, the decision to go to a specialist and visit a doctor for the first time, the consent to start hormone therapy, the submission of an application to the court for gender reassignment in the birth record and (possible) obtaining a court decision in the case, the decision on the surgical sex reconciliation and its execution, subsequent surgeries and procedures in the field of aesthetic medicine.

All the points listed here relate to sex identification, but there may also be certain moments of transition to specific life stages that are crucial from a functional point of view and relevant to the future of individuals with IGIDS. These are: starting school, moving to a new school and environment, adolescent crisis, university education stage, establishing an emotional relationship with another person, taking up the first job, and others).

QUALITY OF LIFE AND LIFESTYLE

Related concepts of lifestyles in social sciences, including sociology, are: everyday life, way of life, custom and ethos [4]. They all find their application in empirical research, but the most commonly used is a lifestyle. The greatest popularisation of lifestyle concepts occurred in sociology in the 1970s. A little earlier the Polish sociologist Maria Ossowska, who described the ethos of chivalry, was a supporter of its use [5].

It is usually indicated that the forms that make up the style have a certain consistency and integrate into specific patterns that constitute pattern series. At that time they are characteristic of a certain style (urban, rural, nouveau-riche, mass style) [4]. The concept of lifestyle is so broad that its use in research may seem problem-free. However, the study of only selected dimensions of lifestyles can lead to abuse in the application of this concept. The comprehensiveness and semantic capacity of this concept have their positive and negative sides.

To put it simply, to define a lifestyle, the daily behaviour of individuals (or social groups), specific to their content and configuration, should be examined [6]. A behavioural and compassionate approach should be indicated in the study of lifestyle behaviours. The first one determines the occurrence of the behaviours themselves, their frequency and dependence on other behaviours. The second one, on the other hand, penetrates into the content and meanings that the individual assigns to the given behaviour. For example, the manifestation by a person with IGIDS of the perceived sex by wearing gender-specific clothing can be considered in these two aspects. The first approach confirms (or not) the occurrence of such behaviours, identifies possible situations where such behaviours have taken place (with or without the presence of others), takes into account the reaction of the environment to such behaviour (consent or prohibitions from parents or being ridiculed or accepted by peers). The second, on the other hand, shows the deeper significance that an individual attaches to wearing such clothes (stressing who one really feels and/or letting others know that one is wrongly perceived by them, strengthening one's own gender identity and consolidating one's own self-esteem).

The use of the lifestyle research category, as mentioned above, may be flexible enough to cover all aspects of life (holistic research) or its selected pieces (selectively indicated life sphere) [6]. In the case of persons with IGIDS, the latter seems to be less cognitively valuable, but also useful. Linking the disorder consisting in the incompatibility of perceived sex with attributed sex has such a strong impact on all spheres of human life that the study of only one of them cannot give a complete picture of the lifestyle. For example, the sexual life of persons with IGIDS may become a selective segment for research, but one should be aware that the results obtained will not reflect the diverse problems faced by persons with IGIDS in their daily lives. Their everyday existence is connected

with many other problems that are directly related to this disorder, but do not concern the sexual sphere [7].

The use of lifestyle categories to obtain appropriate and entangled classifications should be considered [6]. This distinction refers to the already identified problem of researching the overall category of persons with IGIDS (lifestyle of persons with IGIDS) or showing their lives in such a way that they have different relationships, social relationships and dependencies. Due to the already raised aspect of the individual character of the course of this disorder, it seems that it is not possible to obtain a proper classification, i.e. lifestyle characteristics for the whole category of persons with IGIDS. Nevertheless, it is possible to set such a research objective, assuming that these are likely to be lifestyles with a certain common basis, but not a single unified style. In order to determine the classification in the entanglement, it is necessary to take into account those issues that arise from the relationship of a person with IGIDS with his/her closest family and friends and with people from the environment. These are relationships that are significant from the point of view of how these people relate to the condition itself (their knowledge of the condition, awareness of the issues involved, ability to recognize and respond to it) and how they perceive a person with IGIDS (giving help, empathy, mental or financial support, or maybe the opposite – disregard, lack of acceptance, ostracism, stigma and being ridiculed). This includes relationships not only with parents and immediate family members, but also with neighbours, colleagues and friends; pupil – teacher, student – lecturer, patient – doctor, client – lawyer, employee – employer and others relationships. Even the most individualised forms of life have their own social contexts, take place in the social world, and other people are their active participants, silent witnesses or militant opponents.

The quality of life can be determined on the basis of indicators such as:

- easy access to sources (knowledge) that speak about the essence of the disorder,
- psychological care at the stage of problem mentalisation and during treatment (concerning a person with IGIDS and people from his or her environment),
- institutional support for persons with IGIDS or lack thereof (support from psychological and pedagogical institutions),
- access to specialist doctors measured in time intervals,
- reimbursement of the costs of treatment lasting until the end of life,
- the duration of court proceedings for the purpose of amending the entry in the birth record,
- co-financing of surgical, basic and aesthetic medicine procedures,
- desirable educational and professional aspirations and actual implementation (attained levels of education, type of studies, profession learnt and exercised),
- the ease of finding a job,

Section SOCIOLOGY AND HEALTHCARE

- the discrepancy between the desired social status and the actual status achieved,
- forced change of place of residence resulting from the lack of process acceptance process and the fact of sex reconciliation,
- perceived social pressure and the resulting severance of ties with the environment of origin,
- maintaining contact with the family or breaking up with them,
- establishing stable (relatively durable) emotional relations with the partner,
- leading a family life,- having children (fulfilling parental roles even if the children are not biologically linked to the person),
- maintaining friendly relations with people not affected by the disorder,
- concealment of sex reconciliation or confessing to it in the community,
- a sense of continuing life or a sense of breaking its continuity (thinking in terms of „a new life”).

In order to complete the description of the possibilities of using the lifestyle category to study persons with IGIDS, it is worth noting the theoretical approach developed by the Finnish researcher J.P. Ross [8]. In his biographical research, he focuses primarily on the subjective aspects of individuals' life. According to him, such research should include at least four (quite extensive) research fields:

- controlling one's own life: the possibility of influencing one's own life, the feeling that one can decide about it and manage its course. The sociological category of subjectivity [9] may be an equivalent here, i.e. taking effective actions that not only transform social relations and relationships around an individual, but also influence his or her own life;
- the nature of life experiences: a relatively broad category, which includes experience in many spheres of an individual's life; learning experience of social (cultural) roles and at the same time experiencing dissonance resulting from discrepancy in sex perceived and attributed, experience in the sphere of sexual life (not the only one, but significant, because forming a sense of one's own identity/gender identity, as well as sexual orientation), the nature of relations with the environment (with persons with close relationships, but also with members of peer, colleague and friend groups), experiences resulting from attempts to create relationships at different stages of life, experiences related to the sense of "otherness" ("incompatibility") with accepted models of cultural roles, experiencing alienation, isolation and social ostracism as a result of attitudes shown by the environment and others;
- relationship between public and private life: significant in a situation of difficulty with perceived public expression of felt sex, which may result in a desire for conformism in public life while concealing

perceived sex identity in the private sphere (denying the real sense of who one is and manifesting in public life behaviour incompatible with perceived sex, threatening identity crisis or personality disintegration);

- main life orientation: in this case it cannot be narrowed down to understanding it in terms of its own sexual orientation. Although related to sex perception and feeling, life orientation should be broader in scope and relate to the different stages of an individual's biographical life. For example, for persons with IGIDS, decisive moments such as the mentalisation of the problem, the decision to take the therapy in order to reconcile one's sex, taking legal action to change the record in the birth certificate, undertaking surgical procedures to achieve the optimal shape of the desired corporality characteristic of the perceived sex are important. It seems, however, that in the situation of relatively early initiation of therapy (before reaching adulthood) and entering adult life in the shaped form of felt gender, life orientation may be oriented towards achieving other life goals (other than an effort to reconcile sex, important at the "moment" of the decision on the willingness to implement it). The main life orientation is not just a desire for sex reconciliation and its successive, but long-term implementation, but the realisation of other important life goals as a person fully corresponding to his or her felt gender.

CONCLUSION

All the research opportunities offered by the lifestyle category [10] seem to be worthy of being used to identify the problems of persons with IGIDS. Attempts to identify the lifestyles of these individuals, biographical studies of individuals covering all stages in the process of sex reconciliation, is a proposal for comprehensive studies that pose a challenge for sociologists. The determination of the quality of life of persons with IGIDS can be partly derived from such extensive lifestyle research. However, in view of the search for quality of life indicators that could be used in a comparative context, it is possible to use standardised quantitative research, covering a large (numerous) research sample. Surveys allow to obtain rich research material in a short time, at a relatively low cost and using a standardised research tool. The possibility of using specific (identical) questions addressed to respondents provides an opportunity for comparative analysis (for example, the quality of life of persons with IGIDS in different countries or from different social backgrounds). The necessary differentiation of research tools in this case should take into account two cases: IGIDS-M (disapproval of the male phenotypic sex) and IGIDS-F (disapproval of the female phenotypic sex).

In turn, research into the quality of life and lifestyle/lifestyles of persons with IGIDS can contribute to a better identification of the problems of their daily lives and, consequently, improve their living conditions and self-fulfilment.

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