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The Loneliness of a Mother of a Terminally Ill Child. A Research Perspective

Abstract

The mother of a child cared for in a hospice experiences numerous consequences of the illness. One of them is loneliness, which may become a threat for the mother as well as the whole family system. There is still, however, a scarcity of research in this field. The present study, conducted in a qualitative manner, pinpointed the scope and meaning of mothers' loneliness. The analysis of data provided a basis for distinguishing a category of localized loneliness, that is loneliness associated with specific places, such as home, hospital and educational institution, that assumed a new significance in the context of an illness. The loneliness felt by mothers in those places is a difficult experience of an emotional and social nature.

Key words:

loneliness, mother, ill child, hospice, home, hospital, school

Introduction

Loneliness is inextricable from the existence of each and every family; however, in certain cases it takes on a whole new dimension. This is observed when a child's illness, especially a terminal one, enters a family. At this point the very structure and functional model of a family are thrown out of balance. Closeness and understanding become replaced with suffering, stress, tension and the associated loneliness. Virtually every family member is liable to be affected by loneliness, but the mother is at the highest risk as typically being the closest to the suffering child.

Loneliness assumes a special meaning from a pedagogical perspective as it has become one of the most pronounced threats to human development in contemporary times[1]. That is why it is critical to draw attention to the loneliness of mothers of ill children and present its semantic field. It appears that there is still a scarcity of empirical studies concerning the reality of illness and loneliness[2]. The proposed goal of this work will be attained with the use of empirical research of a qualitative nature. The presentation of results will be preceded by a brief overview of relevant literature.

Loneliness in a Family of an Ill Child

A common understanding of loneliness is that of a subjective feeling of a lack of a close person's company or a feeling of abandonment by others[3]. It can afflict any member within a family with an ill child. Child illness upsets the fabric of a family and disturbs the fulfilment

1 J. Mastalski, *Samotność globalnego nastolatka,* Kraków 2007, p. 7.
2 V. Florian, T. Krulik, *Loneliness and social support of mothers of chronically ill children*, "Social Science & Medicine", 1991, 32(11), p. 1294.
3 *Samotność* [in:] *Słownik Języka Polskiego*, retreived March 30, 2015, from: http://sjp.pl/samotno%B6%E6.

of basic tasks, altering them in a number of ways[4]. The family system thus undergoes necessary modifications, observable in the manner it functions[5]. The family starts to be in need of external assistance, has to remain in continual contact with doctors and spend long hours in hospitals or at home. All this is not without consequence for the quality of family and marriage life.

The relationships between family members of an ill child undergo powerful transformations related to stress, and "along with a stiffening of roles the family system grows ever more closed; the family becomes trapped[6]". The stiffening of family roles is related to the need to undertake a wealth of additional duties by the parents, especially the mother. All those factors may lead to a mother's emotional solitude since her reception of her child's suffering is multiplied. In a family where pervasive suffering encroaches upon mutual relationships, attempts to deny stress by family members may occur, especially the fathers. "As a consequence, they distance themselves emotionally from challenging problems, leaving the mothers to address them[7]." It is worth noting that detaching oneself from overwhelming problems need not mean physical separation from the mother since even in a household full of people, female sensitivity may experience loneliness.

A feeling of abandonment and incomprehension is related to the burnout syndrome[8]. A mother's emotional dysfunction may result in her withdrawal from activities and duties towards the child, resignation from attempts to preserve family integrity, or even hostility, both towards other family members and the sick child. Passivity, a strong factor further augmenting solitude[9], may arise alongside stress related to illness. Passivity in initiating and maintaining social ties may significantly hinder the formation of appropriate attitudes, which, in turn, leads to psychological loneliness. A mother's isolation may also be connected with a perceived ineffectiveness or failure of institutions that are there to provide support. Bitter words are usually uttered at hospitals.

The moment of a diagnosis of a rare illness, coupled with a scarcity of information about the child's condition, presents itself as particularly distressing for a mother. Such a situation may be described as a special type of social loneliness in which the people around are not equipped to provide vital information. A lack of time and strength to sustain relationships with other mothers, especially those with sick children, may mean that a woman has no opportunity to discharge her mounting emotions[10]. The feeling of loneliness may be multiplied by a substantial difficulty or even inability for the child to enter the educational system.

Feeling lonely and socially cut-off may be a contributing factor in the rise of moral anxiety. Loneliness connected with spiritual suffering rests primarily on the particular and individual manner that every person lives such experiences. Intimacy as part of the spiritual world limits the ability to explicate such experiences and, consequently, hinders their objectivization.

Literature on the subject approaches loneliness of an ill child's mother from many perspectives, but empirical research will decidedly broaden our understanding of this phenomenon.

4 A. Twardowski, *Sytuacja rodzin dzieci niepełnosprawnych*, [in:] *Dziecko niepełnosprawne w rodzinie*, I. Obuchowska (ed.), Warszawa 2005, p. 47.
5 B. Ziółkowska, *Dziecko chore w domu, w szkole i u lekarza. Jak wspomagać rozwój dzieci przewlekle chorych*, Gdańsk 2010, p. 73.
6 J. Zamorski, *Życie rodzinne jako program wychowania do partnerstwa*, [in:], *Partnerstwo w rodzinie. Istota i uwarunkowania relacji miedzy rodzicami i dziećmi*, ed. J. Truskolaska, Lublin 2009, p. 83.
7 A. Maciarz, *Macierzyństwo w kontekście zmian społecznych*, Warszawa 2004, p. 42.
8 Ibid, p. 44.
9 R. Pawłowska, E. Jundziłł, *Pedagogika człowieka samotnego*, Gdańsk 2000, p. 23.
10 A. Twardowski, op. cit., p. 23.

Research Methodology

The research conducted for the purpose of this work falls within the paradigm of grounded theory in a constructivist approach[11]. Since pedagogical studies allow intermediate forms and combinations of methods[12], the paradigm of grounded theory was confronted with a pedagogical context of the research, and it would appear that the reliability of the study was unharmed. A purposeful selection of the research sample was utilized – analysis parallel to research and open coding.

For the collection of data the method used was that of an open enhanced interview focused on the problem[13] and with the use of a semi-structured interview. Eighteen mothers of children cared for in a home hospice "Alma Spei" were studied. Data was collected in 2014-2015. High ethical standards required by the research were upheld. The investigation yielded research material in the form of recordings that were later transcribed. Subsequently, the recordings were coded and compiled with the use of MAXQDA 11 software according to a qualitative paradigm.

Analysis of Test Results

As a result of the analysis of data gathered during the present investigation a special category of mothers' loneliness was distinguished. It is related to places which, due to an illness, took on a new meaning or whose meaning was in some cases redefined. For the purpose of underlining this type of loneliness it was named *localized loneliness*. The investigation showed that for the mothers in question loneliness was more often than not associated with home, hospital and school or kindergarten.

Although the mothers' testimonies did exhibit traces of neutral or positive connotations of loneliness, loneliness in this work will be presented as a threat, as was set out above. It seems that using the category of *localized loneliness* will enable a deepened understanding of the problem of mothers with terminally ill children.

1. Mother's Loneliness at the Hospital

In the investigated mothers' testimonies loneliness experienced at the hospital revolves around the following three aspects: intellectual, behavioural and emotional. The three types of activity, so fundamental to human nature, have become the carriers of the mothers' solitude. The intellectual dimension of loneliness originated from a scarcity of information about the illness, treatment and post treatment. The unavailability of a reliable diagnosis or receiving multiple negative diagnoses that did not materialize led to a state of isolation and intellectual anxiety. The mothers also spoke of their recurring questions with regard to the child's fate, prospects and treatment. The lack of an answer, not always unjustified, bred fear and insecurity. This may be encapsulated in the following statement: "We knew little because, actually, the doctors said little" (I 12). Conversely, the information about a child's condition and care that parents had was not always taken with due trust and openness by doctors.

The manner of conveying unfavourable information also left a lot to be desired. To illustrate: "I once caught this sentence by the incubator from a nurse to me 'Well, unfortunately the brain cannot be transplanted.' I was so devastated; I cried the whole way…" (I 10). A statement of another mother is slightly less emotional: "From what I've seen so far, if they don't know exactly what to say, the doctors would rather say negative than positive things…. So we tended to hear only negative information, not positive" (I 17). Sometimes the assessment is sterner, as

11 K. Charmaz, *Teoria ugruntowana. Praktyczny przewodnik po analizie jakościowej*, Warszawa 2013, p. 18.
12 B. Smolińska-Theiss, W. Theiss, *Badania jakościowe – przewodnik po labiryncie*, [in:] *Podstawy metodologii badań w pedagogice*, ed. S. Palka, Gdańsk 2010, p. 85.
13 T. Pilch, T. Bauman, *Zasady badań pedagogicznych. Strategie ilościowe i jakościowe,* Warszawa 2001, p. 332.

in the case of the next account: "They just shoot at people and watch their reaction. As if they were sticking a needle in you and just watching and watching (…). And perhaps that is the way they need to be; after all they also lose these kids and watch them die" (I 9).

The unsparing criticism of how medical personnel communicated with patients stemmed from several causes, of which one cannot exclude a lack of basic communication skills or empathy on the part of the hospital staff. Hospitals were those institutions that were frequently rated the lowest by the respondents. The semantic field that was conceived in interviewees' responses seems worth noting at this point. It is comprised of meanings associated with the place where the mothers spent numerous days. Some of the noted expressions include: "It gets to me, I'm cross, I feel clutched, I hate, this continuous threat, horrid, terrible, slaughterhouse". The statements from the mothers show that hospital not only resonated with them emotionally but also somatically. They complained about feeling endangered and lonesome in a large building.

The lives of mothers of hospitalized children were more often than not completely dictated by the visiting hours, the time when they could visit their children and spend time with them. This daily rhythm imposed by the child's illness may have seemed as not allowing any room for loneliness, whereas in reality the case was completely different. A life in constant motion between home and hospital produced a lot of tension and fatigue, while at the same time alienating the mothers from family life. What was problematic was the fact that no place in hospitals was to be found where the mothers could enjoy some comfort. On the other hand, being in an isolation ward further aggravated the feeling of loneliness.

"You can simply go nuts from it. Well, you can, cause there is no-one, there isn't anyone to talk to. When Thomas is asleep, what should I do then? Someone walks along the corridor, maybe knock on the door, so you get a bit of a chat, see someone, talk to them. Other than that you're on your own. No place like home, where there's everyone…" (I 16).

The ability to stay with a child for many hours in conditions that fostered intimacy did not suffice to forestall loneliness. When factors amplifying the feeling of loneliness accumulated, it gave rise to strong emotional reactions that may be described as *crying out loneliness*.

"The other day I just had to cry it all out (…) to my husband. I mean , I didn't really shout at him, I simply had to, you know, vent my spleen, and the fact that I'm kind of alone in all this. It so happened that at that time I was alone" (I 14).

Expressing emotions, even shouting them out, was oftentimes the only way for the mothers to release stress and alleviate solitude; it let them vent their feelings. Sometimes the mothers had difficulty expressing their feelings or lacked courage to show opposition, which in turn caused emotional build-up that led to shedding tears in solitude.

The behavioural area understood as a carrier of loneliness included caretaking activities performed by the mothers. Such activities induced fatigue and in some cases led to exhaustion. In those instances additional assistance from husbands or relatives was needed although not always was it offered with the expected level of empathy:

"I was on my last legs literally (…). I say, 'I can't cope any longer, just come for a night or two.' And then he was there for three nights. And then he says that he kind of gets tired. Don't I?" (I 4).

The husband's reaction clearly shows how difficult it is to overlook or ignore the needs of an ill child's mother. The lack of understanding from close relatives was a factor augmenting mothers' loneliness. The need for a child to stay at the hospital was a painful experience which the mothers nonetheless accepted through their love for their children.

2. Mother's Loneliness at the Kindergarten and School

The ability to enter a child into pre-school or school education was a dream and a challenge for many of the mothers. Oftentimes a child's age or his or her condition did not allow this. But whenever it was possible, the mothers strove for their children to start education. The mothers' testimonies are full of hopes associated with education, even if it was for a special school, described as "a different school but still a school".

Starting education met with difficulties related to a child reaching an appropriate level of maturity. One of our respondents recounted the following difficulties in attempting to sign her child up for school:

"So when we went to the recruitment interview, Kasia virtually didn't show anything. Here I am, talking about how she's doing great, and they are just looking at me 'OK, the mother, right? Well, the mother can say whatever'" (I 13).

A negative evaluation concerning a child's school readiness proved a testing moment for the mother; the experience was additionally painful when ill children of familiar parents attended the same school. Thus a rejection from a school isolated socially not only the child but also the mother.

Oftentimes a child's education necessitated considerable involvement on the part of the mother to arrange the trip to school and back home but also to stay at school with the child. One mother, in order for a school to allow her child, committed herself to being in the corridors every day so that she would be available to provide care for the child if need be. The mother did not express any complaints for the formal requirements, but rather for the school reality and teachers, whose attitude to her presence was unfavourable.

"I was freaking out cause I say to myself, 'God damn it, what the heck is this, I've been here, say, two or three months, and it feels like no one knows why I'm even here (…) Because I'm a guest … it's like I'm not even here, I'm transparent… I'm here, I say, I'm bored, I'm bored stiff! (…) Especially that there's not contact, I happen to be sitting where there's nobody around cause she was in the gym. So I say there's absolutely no one there...' (I 5).

The word *transparent* carries the notion of being unnoticed, overlooked and marginalized. Not being noticed by teachers was disagreeable due to the unsatisfied need to become involved in the child's education. Crying for attention at the same time meant demanding that her rights to care for her child be recognized, and that she would be noticed and appreciated. The school corridor became a place where she experienced social isolation and solitude. Loneliness, which was effectively a trade-off for a child staying at school, was a significant consequence.

It is worth noting the anxiety present in the mothers' statements as they experienced the separation from their children staying in educational institutions. Their testimonies displayed an overtone of uncertainty related to the following questions: "Who is going to look after my child? Will anyone get involved? Who could do it as well as myself? Are they going to discern things in time?" (I 10). Caring for the child was therefore a factor that made it difficult for them to spend their free time in the company of people that might be able to lessen the feeling of loneliness.

Being aware of the limitations imposed by the illness, the mothers strived to find peace and balance in the daily rhythm of activities which, thanks to school going, resembled the lives of mothers of healthy children. It does not, however, mean that this fact helped them to overcome all factors inducing solitude. That is why they sometimes harboured a feeling that their motherhood was different. This being "different" isolated them as well.

3. Mother's Loneliness at Home

The word *home* was quite significant in the mothers' accounts. Home for them was something of an asylum, especially when compared with the hospital. Yet, at the same time it was a place of their continuous presence and, consequently, it was strongly associated with social exclusion: "All the time home, home, home, home, home, home" (I 2). Home thus became a synonym of solitude: "Well, there's solitude. I was used to going out all the time, to being out there in the world, and now all of a sudden at home" (I 16). The loneliness experienced at home was a taxing challenge. To overcome it, it was necessary to go out, which, in turn, meant conquering anxiety. In some cases, this even became symbolic:

"Cause we're practically the whole time at home, and any sort of future that we're creating we're doing so (...) kind of, within these four walls (...). You know, everything is within these four walls. If we get something going here, it happens here. We virtually don't leave here" (I 12).

Going out entailed a change in attitude towards the world outside, namely confronting the people living in completely different reality from that beset by illness. This difference augmented loneliness and tied the family of a sick child to their place of living even more.

Another key word noted during interviews was *silence*. It was brought on the parents by numerous factors, but at its root lay the restriction on their social relationships. A hospital discharge and a referral to a hospice made it possible to return home. However, the atmosphere at home with an ill child was often drastically different from the one prior to the time of an illness. The study of the mothers' accounts proves that silence at home was to a large extent imposed by the sickness, but the mothers' attitudes was not without influence either. One of the mothers, understandably focused on an ill child, strived to adjust the whole family to it, which in effect led to a gradual muting of family activity.

"I've come here, and this silence. Grandma is always out, always on the move, so it's quiet, quiet with little Damian, so I was quite sad, so sad about this silence. Had to turn the TV on or something, otherwise you might have gone crazy at first. Then I got so used to it that now when (...) pop in, or my brothers, I say 'Quiet!' I always said that cause they made such a commotion that I simply got a headache. So I have become used to this silence again and life was what it was but sometimes it was upsetting" (I 3).

This account is significant due to the association of silence with sadness. Therefore, it is not silence as a means to rest or relax. It is usually perceived as a joyless duty that one cannot or even should not try to liberate from as it may disturb the child. Not every home of an ill child was quiet but when silence became one of the rules of family life, then loneliness became sinister and hard to bear.

The third important word is *closure*. In the mothers' accounts it is most frequently used in the context of closing "at home, within oneself, within four walls". The cause of this state was always clearly discernible for the respondents, but closure constituted a major stumbling block in daily life and in caring for a child. "I don't know why, but we closed off. I closed within myself so much. I desperately don't want to go out... I don't feel like going anywhere with her" (I 6).

It is worth noting here that looping considered in the context of sadness and solitude turned into a form of confinement, which it was very hard to get out of. Emotional closure from others restricted the quantity of social relationships and as a result provided additional motivation to remain within four walls. It spurred and boosted the loneliness of ill children' mothers.

Conclusion

The analysis of data gathered in the present study fostered a more profound understanding of loneliness of mothers of terminally ill children. Conceptually, the notion of localized loneliness is not an exclusive or sufficient key to defining the suffering of an ill child's mother. It may, however, be assumed that a sense of loneliness, understood broadly in the socio pedagogical realm, is a daily and hurtful experience, distinctly felt by the studied mothers.

Solitude associated with home, an educational institution or a hospital assumes multifarious semantic shades. The mother is the common denominator, as she functions in those locations and experiences hardship that sets her apart from other people, even if they are around physically. Loneliness thus is a threat to herself and indirectly also to the ill child and other family members.

It would seem justified to recommend that studies of loneliness are continued. Further research may shed new light on the matter at hand and advance the creation of a system of support for mothers of ill children. By the same token, the countermeasures taken by child hospices staff to combat loneliness should also come under scrutiny. Yet another area to conduct analogous studies would be the fathers of ill children.

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