



# Perceptions of Jordanian children with cancer regarding concealing the true nature of their diagnosis: An interpretive phenomenological analysis study

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## ABSTRACT

An interpretative phenomenological analysis approach was used to explore and document the experiences of children diagnosed with cancer regarding the true nature of their diagnosis in the first three months after diagnosis. Face to face semi-structured interviews were conducted with fourteen children diagnosed with cancer and three major themes emerged during data analysis: (1) Surrounded by silence, (2) Confusing the silence, and (3) Try to make sense of the silence.

During the journey to diagnosis most participants reported that people around them conceal the true nature of their illness. Participants were left to their own to make sense of the silence that was surrounding them. This created an unintentional division between the participants, their parents and health team members. This also deprived the participants of important sources of support and compromised their emotional and psychosocial well-being. Jordanian parents and health team members need to follow other countries lead and declare the diagnosis of cancer to children in order to effectively prepare them for the challenges they face to cope with their illness.

**Keywords:** Interpretive phenomenological analysis, children, cancer

**Non-standard Abbreviations:** IPA (Interpretive phenomenological analysis)

## INTRODUCTION

Although research suggests that patients with cancer usually want to know about their diagnoses, prognosis and related treatment,<sup>1-3</sup> many doctors and family members remain more conservative and protective regarding the amount of information disclosed to children who have cancer,<sup>4</sup> Culture and ethnicity appear to be two important factors influencing the amount of information disclosed to patients following diagnosis.<sup>5-10</sup> Western cultures value the principle of patient autonomy leading to doctors disclosing their diagnosis to them even if the information is unfavorable and their family request that the information should be withheld.<sup>4, 7, 11</sup> Conversely, oncologists from countries in Asia, The

Middle East and South America are more likely to withhold information from patients following the family's request.<sup>4</sup>

Jordanian and Arabic cultures do not generally encourage parents to disclose information to their children diagnosed with cancer because they want to protect them to maintain their sense of well-being and provide hope for the future.<sup>4,8,10</sup> It is reported that some patients do not want to know about their diagnosis because they believe that the disclosure of information could be traumatic and shocking and may cause them to make irrational decisions and behave in irrational ways.<sup>14</sup> One major issue that

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previously contributed to this view was the poor survival rates associated with cancer.<sup>15, 16</sup> Arab families and physicians strongly link the diagnosis of cancer with death.<sup>10, 17-19</sup> Therefore, parents do not inform children of their cancer diagnosis to allow them to enjoy the last days of their life. A Jordanian study that investigated the mothers' perception of their children's knowledge of their diagnosis and treatment found that around 60% of the mothers did not communicate what was happening to their child and hid the fact they had cancer by using different names for their illness. They used the word "Leukemia", which has no equivalent meaning in Arabic rather than using the words "Saratnfeeldam" which translate to "cancer in blood" in English.<sup>20</sup> Other studies have reported similar findings.<sup>21,22</sup> Regardless of the abovementioned perceptions, several researchers agree that non-disclosure of information to cancer patients is viewed as a breach of the patient's right to autonomy because they are unable to consider their future from an informed perspective.<sup>11, 23</sup>

The above studies have discussed the disclosure of information issue from physicians, parents' and relatives' perspectives only without discussing the perceptions of patients themselves. There was a need to explore this issue from patients' perspective. Therefore, this study was completed to detail the perceptions of children with cancer regarding concealing the true nature of their diagnosis in the first three months after diagnosis.

## MATERIALS AND METHODS

Interpretive phenomenological analysis (IPA) methodology was used to explore and detail the lived experiences of Jordanian children diagnosed with cancer in the first three months following diagnosis. This methodology is useful when there is a paucity of information available about phenomena under study. It allowed the researcher to obtain rich description of participants' experiences<sup>24, 25</sup> and to interpret the meaning of the experience. Fourteen participants

were interviewed between January and June 2010 at two Jordanian hospitals. Eligible participants were between 13 and 17 years. Ethical approval to conduct this study was gained from university and hospitals ethics committees. Audio-taped -semi- structured interview were conducted in a mutually agreed place with the children who were accompanied by their parent(s). Voluntary consent was gained from the participants and their parents before conducting the interviews and confidentiality was ensured through the use of pseudonyms.

## DATA ANALYSIS

Interviews were transcribed verbatim and were analysed using the method described by Smith et al.<sup>26</sup> Data were managed by using ©QSR NVivo8 software. Transcribed data were coded and divided to small meaning units from when they began to emerge. These were then collapsed to constitute major themes.

## RESULTS

Fourteen participants aged between 13 and 17 years old and diagnosed with cancer agreed to participate and were interviewed. Demographic data on participants is detailed in Table 1.

**Table 1: Profile of participants**

Item	N	%	Item	N	%
<b>Participants' Age</b>			<b>Participants' Diagnosis</b>		
13.00	5	36.0	Hodgkin lymphoma	5	35.0
14.00	2	14.0	Non Hodgkin lymphoma	3	21.0
16.00	3	21.5	Leukaemia	6	44.0
17.00	4	28.5	<b>Participants work</b>		
<b>Gender</b>			Student	13	93.0
Male	9	64.0	Farmer	1	7.0
Female	5	36.0	<b>Parents' Income/ year</b>		
<b>Type of Treatments</b>			Less than 3000JD	10	71.5
Chemotherapy	14	100	4000-6000 JD	3	21.5
Radiotherapy	0	0	7000-9000 JD	1	7.0
Bone Marrow Transplant	0	0			

Three themes were emerged from this study (1) Surrounded by silence, (2) Confusing the silence, and (3) Try to make sense of the silence. Each of these themes will now be presented and supported by participant quotes and researcher interpretations.

### (1) Surrounded by silence

While parents were initially told of their child's cancer diagnosis, the emotional impact of the event caused them to remain silent and to not share this information with their child. Similarly, doctors directed their communication to the child's parents often excluding the child completely from the discussion. As a result, participants were surrounded by silence and were unable to understand what was happening around them. One participant first became aware that something was wrong with her by the way her doctor interacted with her. Doctors in public hospitals are very busy but Khloud became acutely aware that her doctor accompanied her when she went to get her blood test results. She also noticed his reaction to the test results and his attempt to hide this from her. Although he remained silent, his body language changed indicating to her that something was wrong and what he had read was not good news:

They [doctors in hospital] told me to go and

get [biopsy results]. One doctor accompanied me.... When the doctor read the results, he was shocked and he said to me "don't worry, everything is OK". I felt that there was something wrong, but he didn't say anything at all. (Khloud 16 year old)

Another participant attempted to find what was wrong with him but his family would not share what they had been told him. Although Sami noticed the changes in his family's behaviour, and that the name of the hospital to which he had been admitted contained the word cancer, he initially denied that he had cancer. Denial is an important defence mechanism that assists individuals to cope during times of intense stress:

He [dentist] gave the result to my family [that I had cancer]. .... No one told me about that... All the family members knew about my situation except me. [Pause] One morning I found that my older brother had awakened early [to join Sami to go to the hospital]. That was strange because he doesn't care for anything other than his work. ... Then my uncle arrived. When we arrived to [KHCC],

doubts began to invade me. I lied to myself, telling my uncle we are not in cancer hospital we are in the University hospital. (Sami 17 year old)

Mona also came to know about her diagnosis from a doctor as a result of his conversation with other doctors standing around her in bed. The doctor underestimated her capability to comprehend the real nature of her illness but she was able to deduce from their conversation that she had cancer. She responded to the silence from those around her by also being silent. While she was aware she had cancer she had little understanding of what this actually meant as the conversation between the doctors occurred in English, which she did not fully comprehend:

Nobody told me about my diagnosis, I found out myself. From the way that the physicians talked and from the medicines I took [Mona figure out she had cancer]. [Pause] No one knew that I was aware of my diagnosis and I did not discuss my concerns with anybody. (Mona 13 year old)

Although silence was a common experience for all of the participants, they experienced different types of silence. Some were totally unaware of their diagnosis while others decided to remain silent about what they knew in response to the silence surrounding them. However, the one common denominator in the experience of silence for these participants was the persistent silence from their parents as to what was happening to their child. As a researcher I interpreted that this represented a continuous source of discomfort for these children.

## (2) Confusing the silence

While parents did not communicate verbally with their child their conflicting verbal and non-verbal responses added to their child's feeling of confusion. Parents often broke down and showed displays of grief, for example, crying because they felt overwhelmed by the events unfolding before them in relation to their child's illness. The resulting confusion became central to the theme of *confusing the silence* and Khloud's mother demonstrated confusion in message transmission very well. Khloud received her first dose of chemotherapy while her parents

remained at home, when they later telephoned her to enquire about her well-being Khloud felt confused and concerned about her mother's response to her laughter:

...After that [my chemotherapy session] my mother called me [to ask about my health] on the phone and I started laughing, so she told me "I am losing my nerves and you are laughing?" I asked her "are you worried about me?" she started crying without giving me any explanations. I was unable to explain this [my mother's response]. (Khloud 16 years old).

While Khloud did not discuss her diagnosis with her mother she witnessed her mother crying without providing any explanation for this behaviour. This confused Khloud and increased her level of distress but her mother continued to maintain her silence. While the confusion of silence contained a strong familial wish to protect Khloud, it introduced a paradox whereas the desire to protect actually caused further distress.

Traditionally, Jordanian men are expected to control their emotions when confronted with difficult life events. This expectation played out in Yousef's family through the relationship between Yousef and his father. They did not show emotion in-front of each other and Yousef's father had to appear as if he was always in control of family issues and problems. However, when he was hospitalised, Yousef's mother displayed an outpouring of emotions; she cried in-front of her son but without explanation:

... I became sad and started crying with her [my mother] and told her "mum don't cry, God will dispel my trouble" [cancer], she stopped crying and went outside to cry so she would not be seen and did not upset me. ... I saw my father secretly crying but not in front of me. [Researcher: Did you ever cry in front of him?] No, I don't cry in front of him. Because I am a man and man should always be strong [not cry]. (Yousef 13 year old)

For Yousef, the paradox contained in the silence became evident and while his parents demonstrated strong emotions to his diagnosis they did so in secret without his knowing. As a result of the silence Yousef felt helpless to assist his parents, which signalled



another stressor for him - observing his parents experiencing stress and abnormal emotions.

Mona's parents also conveyed contradictory communication in their interactions with her. They cried when they were told about their daughter's diagnosis but they did not explain the reason for their behaviour to her and assured her she was alright and would get better:

While I was out of the room, they [doctors] talked to my father and mother, and once the doctor started talking to my mother [telling her that I had leukaemia] and I had to receive treatment [chemotherapy]. My mother started weeping [pause]. Mum cried and wept, my father wept also. [Pause] In the car I asked them about the situation? My mother just cried and my father told me there was nothing to worry about and then there was silence. I was confused between their contradictory responses. (Mona 13 year old)

Mona asked her parents about their differing and changing emotional states but was told there was no need for her to worry. Her phrase "and then there was silence" is telling, because the silence acted as euphemism for we will not discuss this very difficult subject anymore.

In summary, participants were surrounded by a silence that confused them and hindered their communication and increased both their own and their parent's level of stress. Silence prevented the participants from being able to talk to their parents and as a result the silence left participants to their own resources to make sense of what was happening to them.

### **(3) Trying to make sense of what is happening in the presence of the silence**

Even with the presence of silence from those around them, participants began to start to understand what was happening to them through their fears, past knowledge, and memories of the cancer experiences of other family and friends. For example, Ali received little formal information from health team members and was left to contemplate what was happening to him in silence. In processing the information he was receiving from those around him he tried to obtain

different explanations about the cause of his cancer as a way of minimising his feeling of anxiety and uncertainty:

No one told me anything [about the cause of his cancer] but I think the reason [for my cancer] was because I had seen a mass on my neck and I did not visit a doctor. I think this was the reason, um [pause] it might have been because I neglected the mass on my neck or I think it was due to a virus, [pause]. Sometimes I think there is no reason because it appeared suddenly, but when I reconsider the situation, I think it was a virus that affected my body. (Ali 16 year old)

Other participants linked the cause of their illness to such things as extraordinary powers, like God and magic. Haneen thought her diagnosis of cancer was a test from Allah and her answer to the researcher's question portrayed this belief: "My illness [cancer] is from Allah and we should remain patient". From an Islamic perspective, when some Muslims ascribes the cause of any illness by way of saying "this is Allah's will", it means such an event is beyond the ability of the person to control. Therefore, Muslims are expected to accept this and not question what is happening to them. Haneen's answer to the question about the cause of her cancer also implied that she wanted to stop the researcher from asking further questions because they may increase her stress. Haneen was young and she established a culturally convenient statement to stop people from asking more questions about her illness. My interpretation was that Haneen was trying to respond to her family's silence using silence, and supported this in the following way:

My illness [cancer] is from Allah and we should be patient. [The patient's facial expression is calm (Field note 1, 28th March 2010)]. [Researcher: Why?] This is Allah's will, and anyone could suffer from a cancer [pause] we cannot question Allah's will. (Haneen 16 year old)

There is a sense that Haneen adopted this general explanation, as she believed that Allah controlled everything and she accepted that the cause of her illness was derived from an extraordinary power

(Allah) and, as such, she was obliged to accept her fate.

Other participants believed, in the presence of silence, that the cause of their cancer was "magic", and in particular the process of "envy". In Jordan some people traditionally believe that if they wear new clothes, and if they are recognised as being successful in their work, or have a beautiful body shape, and/or a healthy body, other people will view them with "envy".

Two female participants in this study prior to being diagnosed with a cancer were healthy, happy and beautiful. However, they believed that they had been subjected to envy because people were jealous of them and, as a result, they developed a cancer. Although Khloud was aware of a biomedical cause of her illness, the process of "envy" still played an important role in how she conceptualised the cause of her cancer. Therefore, because she received no further knowledge and understanding of her illness from health team members she was forced to make her own interpretations of what had caused her cancer:

... The reason may be that [pause], I do believe in envy. In the past, I used to wear beautiful clothes and do things that made people envy me, so maybe some people envied me (Khloud 16 years old).

In the presence of silence, Khloud linked her current condition to the extraordinary power, which in her case, was envy, a kind of magic that she unable to resist.

In summary, in the absence of the ability to openly discuss the cause of their illness, participants were left to process what information they could collect from a variety of sources in order to assist them to make sense of the situation they had now found themselves in. As participants had different life experiences and levels of education their beliefs regarding the cause of their illness also differed.

## DISCUSSION

During the process of diagnosis, participants were surrounded by silence, which included the silence of

their parents, families and health team members. The created silence was dangerous because effective communication between family members was damaged and the children found themselves alienated from the sources that provided them with information during times of stress.

A danger associated with silence for patients with cancer is the risk of the development of disabling comorbidities such as clinical depression and anxiety. It also affects patients with cancer level of satisfaction with treatment courses<sup>27-29</sup>. Depression as a comorbidity had a dramatic impact on all areas of care and can double the length of stay in hospital and impact significantly on the individual's health decision making processes and long term outcomes<sup>30,31</sup>. Eapen and Revesz<sup>29</sup> found that lack of communication between family members was found to be a significant factor which altered patients coping mechanisms and increased their level of stress. Parents need to be informed that globally the emphasis is on informing affected children about their diagnosis and assisting them with family support to adjust to the changes in their lives<sup>32-35</sup>.

Participants in the current study could not interact with health team members effectively and /or ask for information because of the silence. However, previous studies where children were told of their diagnosis they then continued to request further information and to be fully informed of what was happening<sup>36-39</sup>. Firstly they required useful tips on how to improve their appearance to cope with the effects of chemotherapy<sup>36,38,39</sup>. Secondly, they wanted education about their illness and how to live a productive lifestyle seeking information on exercise, nutrition, complementary and alternative health services, infertility information, and mental health counselling<sup>39</sup>. Thirdly, they wanted to know how to cope with embarrassing situations<sup>36</sup>. Participants also reported their need for more information regarding their illness such as, the possibility of the illness recurring, the effects of drugs on participants.<sup>36</sup>

Children in previous studies focused on their educational need compared with participants in the current study who were fairly able to recognize their real diagnosis and the reason for their frequent visits

to hospital. Therefore, participants in this study need more educational classes' aims to address the previously mentioned educational needs. Pre-awareness of their illness and good education regarding the coping mechanisms could help participants to avoid future complications before they occurred.<sup>40</sup>

Jordanians health team members will need also to be aware for patients' psychosocial needs to assess for and intervene to prevent or effectively manage comorbidities such as anxiety and depression if they occur.<sup>32, 37, 41, 42</sup> Lastly, this study was limited to small homogenous sample group, therefore, further studies including larger sample size are required.

Overall, with all efforts of health team members and parents to conceal information from participants they were able to deduce their diagnosis. The ultimate product of silence was compromising children with cancer journey. Because of the silence, participants were exposed to unnecessary negative experiences and left to fumble on the dark alone without important source of support. Effective communication between all parties can help children with cancer to overcome obstacles they experienced during their journey.

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