

Social Interaction of Cancer Survivors in Malta. A sociological analysis

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Abstract:

This research analyzes social interaction of cancer patients in Malta. In particular it applies a qualitative sociological approach to verify how cancer patients interact with family members and society. The research concludes that social interaction of cancer survivors in Malta is characterized by mixed experiences, but at the same time, all cancer patients emphasize the importance of family support. A major finding is that cancer patients do not simply receive support from family members, but also provide it themselves to their relatives. This is not an intended effect of cancer survivorship, but nevertheless it helps strengthen social bonds within families of cancer patients.

Keywords:

Cancer, sociological factors, social networks, social capital.

Introduction

This research analyzes social interaction of cancer patients in Malta. In particular it applies a qualitative sociological approach to verify how cancer patients interact with family members and society.

This study was inspired by three main motives. First, one of the authors experienced cancer in her family and was prompted to analyze the challenges and interpretations of cancer patients sociologically. Second, this study aims to explore whether cancer patients relate to their illness in a fatalistic manner, or whether they give more importance to survival. Third, this study aims to raise awareness in academic and policy fields on the social dimension of cancer.

Cancer in Malta

Every year, in Malta, around 1,400 people develop Cancer, eventually resulting in the death of around one in every four.¹

A Eurostat report published early in 2016 showed that in 2013 Malta had the highest shares of female deaths due to breast cancer in Europe, together with Cyprus. This was the cause of 21 per cent of deaths due to cancer among women in the two island states. The EU rate was 16 per cent. On the other hand, Malta had the lowest percentage of prostate cancer rates in the European Union, together with Italy, Luxembourg, Poland and Slovenia. The 8 per cent rate was lower than the EU rate of 10 per cent. The report also highlighted that lung cancer was the most prevalent fatal form of cancer in the EU and then men were more likely to be killed by cancer than women.²

At the same time, according to EUROCORE-4,³ cancer survivorship in Malta is increasing. This includes survival rate in the two most common cancers among females and males respectively, namely breast cancer and prostate cancer. However, compared to the European rates of Cancer survivors, Malta still has lower rates of Cancer survivors than that of the European

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average.⁴

Of direct relevance to this study, Malta's National Cancer Plan (2011-2015) refers to the patients' perceptions on Cancer. In its words:

“A diagnosis of Cancer brings about a great deal of psychological distress in patients and their loved ones. This includes an increased uncertainty about the future, emotional instability, increased dependence on others, reduction of self-esteem and the perceived threat of possible death. Such distress puts Cancer patients at increased risk of developing psychological disorders”.⁵

Within the context of Maltese society, a small-island state with a relatively high degree of family proximity (for example, through quasi-modified extended families and the coexistence of modern and traditional values),⁶ social solidarity,⁷ altruism,⁸ and a hybrid welfare state,⁹ it is of sociological relevance to verify whether social bonds of cancer patients are enabling them to cope with their experiences.

This specific dimension of cancer is under-researched in Malta. Apart from the undergraduate dissertation by Charon Tedesco¹⁰, which provides empirical data for this article, other studies in the field deal with men's experience of their partners' breast cancer experiences¹¹, social work with family members of children with cancer¹² and with carers of terminally ill patients¹³, young people and parental cancer¹⁴, awareness, education and prevention of cancer for women¹⁵ and for women with disability¹⁶, and breast cancer and women with disability.¹⁷ A common thread among these studies is the emphasis on the need for professional psychosocial services for persons in such situations.

Social aspects of illness

Caplan claims that social support is fundamental in helping patients with a chronic illness to adjust to their new situation.

“Social support can exert major influence on a client's ability to cope with a chronic illness. An individual's coping responses during crises are influenced not only by his or her ego strength, but also by the quality of service and emotional support provided by the social network”.¹⁸

Parsons regards illness as a legitimate type of deviance, as “the sick person is not regarded as responsible for his condition, he can't help it”.¹⁹ This argument is debatable in a welfare context where citizens are held increasingly responsible for their life-choices, but nevertheless health systems such as Malta's provide universal assistance to cancer sufferers. Parsons adds that the sick person is free from normal social responsibilities and has the right to be taken care of.

Along the same lines of Parsons, Bury says that persons experiencing chronic illness are largely dependent on others, and that this can disrupt their mutual give-and-take relationship, as the chronically ill person is unable to assist those helping him. Hence chronic illness is seen as a “disruptive force”,²⁰ and sufferers tend to withdraw from normal social interactions.

Goffman says that persons with illness might be concerned with the possible experience of social stigma. In this case, they might hide their illness, especially if it is not physically visible, thus giving the impression that they are ‘normal’. This social technique is referred to as ‘passing’.²¹

Such situations may be stressful, where such individuals “must necessarily pay a great psychological price, a very high level of anxiety, in living a life that can be collapsed at any moment”.²²

If cancer is present on a visible part of the body such as the skin, sufferers might find it more difficult to conceal their situation. In such a case, the sufferer might possess “stigma, an undesired differentness from what we had anticipated”.²³

Stigma might also take place when sufferers cannot carry on their everyday life. They might be labelled as helpless individuals. Yet,

“The stigmatised individual tends to hold the same beliefs about identity that we do; this is a pivotal fact. His deepest feelings about what he is may be his sense of being a ‘normal’, a human being like anyone else, a person, therefore, who deserves a fair chance and a fair break”.²⁴

In some cases, stigmatised persons may try to ‘fix’ the cause of their stigma.²⁵ For example, in the case of breast cancer, women might undergo mastectomy and subsequent breast reconstruction.

A more positive outlook on social aspects of illness has been provided by Putnam.²⁶ His social

capital theory focuses on the positive contribution of social cohesion, reciprocity, trust and similar social factors. As regards health, Putnam argues that social networks can provide material assistance and consequently reduce stress, they can reinforce norms of healthy lifestyles, they can help advocate better medical services and can help stimulate the body's immune system.²⁷

Some empirical sociological research on cancer survivorship deals with concepts such as social networks and stigma respectively. For example Norberg et al²⁸ carried out a follow-up study on female breast cancer survivors 5 to 7 years after being operated upon. Some themes that emerged from discourses among survivors were the importance of social networks, the perceived importance of women's caring roles and other gendered differences. Positive thinking and being physically active were also emphasised as examples of individual responsibility.

Martinez-Ramos et al²⁹ found that female cancer survivors feared being stigmatized if they talked in public about their experiences, and that their female identities might be perceived negatively. They also emphasized the importance of social networks with families and communities, for example in social support and provision of care. Respondents also viewed advocacy of their

experiences as important to help empower cancer survivors.

Kaiser³⁰ discovered different, and at times conflicting, interpretations of the term 'survivorship' among women who experienced breast cancer. These varied from feelings of alienation due to fear of recurrence of cancer to wishes to keep one's experience private.

Methodology

As stated above this study attempts to analyse social and family support of cancer patients in Malta. In order to answer this question, a qualitative-interpretative approach was used in order to enable respondents to open up on their life experiences.

For this purpose, semi-structured face-to-face interviews were carried by one of the authors of this article, Charon Tedesco, with 11 former cancer patients who were identified by a general practitioner, with the approval of the University of Malta Research Ethics Committee (UREC).

Respondents included three males and eight females, who gave their informed consent to being interviewed at their respective homes, on condition of anonymity. The following table explains in more detail:

Table 1: Respondents' social background and type of cancer

Fictitious name of Interviewee	Gender	Age when Diagnosed with Cancer	Type of Cancer	Cancer stage	Occupation
Manuel Falzon	Male	59	Large intestine Cancer	Stage 3	Construction
Noreen Galea	Female	43	Breast Cancer	Stage 3	Housewife
Mandy Cauchi	Female	40	Breast Cancer	Early stage	Housewife
Claudia Bugeja	Female	40	Breast Cancer	Advanced stage	Housewife
Rose Tanti	Female	38	Bowel Cancer	Malignant stage One	Businesswoman
Karen Mifsud	Female	45	Breast Cancer	Early stage	Housewife
Ramona Dalli	Female	53	Thyroid Cancer	Early stage	Housewife
Natasha Vassallo	Female	45	Uterus Cancer	Stage 3	Housewife
Nadine Borg	Female	44	Thyroid Cancer	Early stage	Housewife
Joe Borg	Male	65	Prostate Cancer	Early stage	Pensioner
Craig Thomas	Male	58	Skin Cancer	Early stage	Construction

It has to be emphasized that the qualitative methodology of this study precluded representative sampling. What this study provides is an in-depth study of the experiences and narratives of a convenience sample of cancer survivors. Besides, for ethical and practical reasons, the authors could only select participants through snowballing thanks to a gatekeeper, namely a general practitioner who offered to select persons of his trust deemed fit for this study. Other respondents could have had other interpretations of their experiences. But it has to be emphasized that the strength of this study is in the depth of the narratives provided by respondents.

Notwithstanding the above, the authors ensured that bias was avoided in the research process. The standard procedures of semi-structured interviewing were carried out, and responses were analysed systematically in relation to the conceptual framework of the study. Given the nature of this study, it was concluded that face-to-face interviews were more appropriate than other methods, so as to ensure maximum trust from respondents.

The interviews were conducted in the first months of 2013. All respondents were asked the same questions in the same order. Some respondents required prompting and further explanation of certain questions.

The first questions were descriptive, thus focusing on the respondents' background. These were followed by questions on the respondents' reactions to their cancer diagnosis and on their social relationships with relatives and medics. Respondents were then asked about their lives before and after cancer and about their experiences as cancer patients. Subsequently, respondents were asked about coping with cancer and about their outlooks about their respective futures.

The process commenced with two-pilot studies from which no problems emerged. One particular respondent required assistance from his spouse who articulated his thoughts. All interviews were recorded and the case-summary method was used for transcription.

In most cases, respondents were interviewed alone, but there were some cases when a respondent's spouse would be present for the respective interview. Interviewees were asked questions directly linked to the scope of this article together with other questions related to coping strategies and self-identity.³¹ All interviewees except one were open and looked comfortable in

sharing their experiences during Cancer. The exception regarded a respondent whose responses were made by his spouse as she stated that he was very introvert and preferred keeping things for himself.

Through their sociological imagination, the authors of this study believed that respondents' views would be very much related to the severity of their cancer, to their general outlook on life and to their social situations such as family background. These opinions helped inform the research questions of the study, but only after a thorough literature review was carried out, thus informing the research process systematically. On the other hand, certain findings went beyond what authors were expecting. A striking example was one which emphasized the support given by cancer patients to their significant others, as explained later on in this article.

It is important to emphasize that even though responses provided a high degree of validity, due to the production of information which reflected the real life experiences of cancer patients, the responses can in no way be deemed as being representative of cancer patients in Malta and beyond.

Findings

Mixed Social Interactions

The cancer experience had mixed impacts in terms of participants' interactions in social life. Some carried on with their regular social activities, whilst other withdrew from social interaction apart from that concerning their family life. Yet most participants did not feel stigmatised by others. But this only happened because they did not disclose their illness to non-family members, as they feared the social repercussions of being exposed. Hence, the spectre of stigma haunted some participants of this study.

One universal commonality among participants was their expressed need to communicate about their illness with their respective families. They felt the need to open up about their respective cancer experiences.

Karen Mifsud, for example, wanted to be left alone at times, but also wanted to open up about her experience with someone. Family members were very important in this regard. The same line of thought was expressed by other participants who did not feel comfortable talking to non-family

members about their illness. One participant, Nadine Borg, had told her neighbours and friends when she had previously experienced appendix, after she spent time in hospital. But she did not do the same when she experienced cancer.

Participants such as Noreen Galea and expressed their need for quiet, away from the everyday social interaction.

“I avoided people to avoid talking about my illness and also I looked for quiet places away from people”.

Yet, other participants felt the need to disclose their cancer experience to strangers, friends and neighbours.

Manuel Falzon, for example, said that he did not mind speaking about his cancer experience with such persons. As he put it, “there is nothing to be ashamed of”. Claudia Bugeja’s perception was along the same lines, stating that she talked about her experience with different people she encountered.

Natasha Vassallo stated that she felt more comfortable discussing her experience of Cancer with other patients who were going through the same experience.

“At first, I kept everything for myself but then I found someone going through the same experience and gave me the strength not to give up”.

Some others felt that if they spoke up about their experiences, this could be beneficial to other cancer patients. An interesting example in this regard was of Joe Borg. An introvert personality, he relies very much on his wife for social interaction. And his wife actually related to his experiences to encourage other cancer patients to face their situation with a positive attitude.

Strengthened Family Bonds

All of the participants participating in this study argued that Cancer brought their family members closer to each other, strengthening their bonds.

Most participants found support from their families. Families provided support for the former Cancer patients.

“After being diagnosed with Cancer, bonds between family members became stronger and cohesive... I wanted to spend as much time as possible with my family. During my illness, relatives used to call or visit every day to check up on me” (Mandy Cauchi).

Some other participants, especially those whose cancer was diagnosed in its early stages, did not note any major difference in their family relationships. A case in point was Craig Thomas who was diagnosed with skin cancer.

The fact that most family members provided support to the participants is hardly surprising, also especially due to the strong family bonds that exist in Maltese society. However, participants showed that their situation was not simply dictated by a one-way process of relatives providing assistance to patients. Indeed, most participants stated that their illness initially had a negative impact on their relatives, who experienced sadness, fear, anxiety and anger. Many felt lost and preoccupied about their loved ones’ chances of survival. Hence, coping strategies for relatives of patients were also required.

One of the participants, Manuel Falzon explained that his wife shared his cancer experience with their relatives on her family side. This was mainly the case as she herself needed to cope with this new situation, and thus felt the need of support from relatives.

Participants gave importance to their family bonds in relation to the provision of courage and determination to fight the illness. For example, Karen Mifsud said that she fought against cancer “because I have my daughter to live for”. In such cases, family relationships provided a sense of obligation.

Another participant, Noreen Galea was concerned about her children’s thoughts, questions and anxieties related to her illness. Indeed, there were cases where family members felt more scared and lost than the patients themselves. Manuel Falzon’s wife, for example, stated that

“When my husband was diagnosed with Cancer, I felt more scared than him, especially during the first treatment of chemotherapy.”

Mandy Cauchi asserted that

“Even though my husband always acted courageously, during Cancer, he needed my help to survive”.

Rose Tanti expressed how her illness affected her son’s behaviour. He *“became distant and withdrew from his friends and social activities”*.

Therefore, apart from being reliant on the support of family members in relation to their illness, participants in this study asserted that support was two-way, as they themselves helped their family members to cope with the situation. In a clear case of reciprocity, respondents relied on family support but, in turn, were also a source of support for their loved ones.

Besides, the cancer experience also helped relatives become more aware of the illness, and in some cases encouraged them to conduct checkups more frequently.

As regards family relationships, therefore, the cancer experience had some unintended positive outcomes. Family members tended to get close together, and support was two-way, where cancer patients themselves often provided support and encouragement to their loved ones in their coping strategies.

Discussion and Conclusion

The findings of this research show that social networks of cancer sufferers may be of great value as they provide support and reciprocity. This is two-way, as apart from the support given by relatives to sufferers, this study also revealed that sufferers can offer moral support and encouragement to their loved ones as they try to cope with the new situation.

In this regard, Putnam emphasizes the value of social networks characterized by people’s relationships. He refers to “connections among individuals- social networks and the norms of reciprocity and trustworthiness that arise from them”.³²

Judging by the findings above, chronic illness can also be theorised in terms of positive and unintended outcomes. In this regard, Merton’s theory of latent and manifest functions is of great relevance.³³ Manifest functions have intended consequences, yet society is also characterised by latent consequences, which were not expected or intended.

In the case of cancer sufferers, example of

latent consequences were the development of new friendships with other patients, the increased closeness with family members, and the support given by sufferers to their own relatives.

This research has shown that social interaction of cancer survivors in Malta is characterized by mixed experiences, but at the same time, all cancer patients emphasized the importance of family support. A major finding of this research is that cancer patients do not simply receive support from family members, but also provide it themselves to their relatives. This is not an intended effect of cancer survivorship, but nevertheless it helps strengthen social bonds within families of cancer patients.

Given the importance of family bonds among cancer patients, it is recommendable that Health authorities invest more in counseling and other support services to families experiencing such situations, and in providing functional equivalents for cancer patients who do not have close family bonds. Therefore, Malta’s welfare system should ensure that social networks of trust are universally accessible to all cancer patients, irrespective of their social background.

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