INDEX DE ENFERMERIA
BIBLIOGRAPHICAL INFORMATION, RESEARCH AND HUMANITY

Index de Enfermería, 2020; 29(1-2): e12590e
http://ciberindex.com/c/ie/e12590e
ISSN: 1132-1296

ORIGINALS

Paper receiver: 11.09.2019
Paper accepted: 21.11.2019

Sexuality experiences in adult patients diagnosed with leukemia and undergoing chemotherapy

Carolina PINEDA GUTIÉRREZ,[1] Dora Isabel GIRALDO MONTOYA,[1] Hernando RESTREPO PAYÁN[2]
[1]Facultad de Enfermería. Universidad Pontificia Bolivariana. Medellín. Colombia. [2]Facultad de Medicina. Universidad Pontificia Bolivariana. Medellín. Colombia

Correspondence: carolinap5618@hotmail.com (Carolina Pineda Gutiérrez)

Abstract
Main objective: to describe sexuality experiences in adult leukemia patients undergoing chemotherapy. Methodology: exploratory qualitative study of phenomenological trend, with eight participants and two in-depth interviews with each one. The analysis consisted in gathering information and tracking topics. It aimed at grasping the essence, encouraging new topics, and delving into the meaning of the experience. It was approved by the Ethics Committee. Main results: three analytical topics emerged: (1) relationships are strengthened, (2) sexual desire is inhibited due to the disease, and (3) there is a need for information on sexuality. Main conclusion: sexuality is expressed in interpersonal relationships and family interactions. Sexual desire is inhibited because there are other priorities. It is necessary that healthcare professionals provide their patients with relevant information on sexuality.
Keywords: Leukaemia. Drug therapy. Sexuality. Nursing care.

Introduction

Leukemias are a heterogeneous group of diseases characterized by infiltration of the bone marrow, blood, and other tissues by neoplastic cells of the hematopoietic system, which, according to their evolution, are classified as acute or chronic and, according to the cell lineage affected, they are lymphoid or myeloid.[1] In Colombia, the estimates suggest that every year there will be about 1,338 new cases of leukemia in men and 1,290 cases in women.[2] Treatment for people with leukemia requires inpatient hospitalization due to daily hematological monitoring and the aplasia produced by the drugs. The toxicity of antineoplastic drugs depends on the type of drug, the chemotherapy regimen, the dosage, the route of administration, the elimination pathway, and also the synergism among this components.[3]

One of the effects of the treatment is that it may alter sexual functioning as a result of symptoms such as fatigue, pain, and restriction of movement.[4] Furthermore, anemia and anorexia may cause weakness and also hinder sexual activity.[5]In addition, the treatments used (drugs, radiotherapy, and surgical interventions) may produce similar effects and even considerably limit sexual relations. Psychological factors such as beliefs, the emotional impact of the disease, motivations, and coping play an important role in the appearance of sexual difficulties.[5,6]

According to López and González, there are four main ways in which cancer or its treatments can affect sexuality: (1) physical problems to give and receive sexual pleasure; (2) disturbed body image; (3) feelings such as fear, sadness, and distress; and (4) modification of roles and relationships. If one of these problems arises, there may be an impact on the others.[7,8] Many of these manifestations tend to be underestimated by the health care staff due to lack of information or knowledge on the subject or because of fear or embarrassment to address a topic that can be questioned from a cultural and social perspective.[6]

Some studies have demonstrated the importance of supporting cancer patients regarding their sexuality during and after treatment.[9,10] Olsson et al. found that nurses caring for cancer patients considered sexuality as an area of their professional responsibility, but they rarely provided support in that respect.[11] Nursing professionals could guide the implementation of various intervention approaches[12] to support sexuality during and after treatment. According to Schover et al., many cancer patients are not aware of potential changes to their sexual function or fertility; even after treatment, they continue to have unmet needs for information.[13]

Nurses need to prepare to provide solutions, information, and guidance about the sexual problems of their patients through life experiences, which are unique and diverse. In this sense, qualitative research is a very valuable tool because it proposes new ways of caring, beyond the biological aspect, and prioritizes humane care. From this perspective, the present study seeks to describe the sexuality experiences of adult

patients diagnosed with leukemia who are undergoing chemotherapy.

Methodology

This was an exploratory qualitative study of phenomenological trend. The population was represented by patients hospitalized in the hematology and oncology unit of a healthcare institution in Medellín (Colombia), who met the inclusion criteria: aged 18 years or older, diagnosed with myeloid or lymphoid leukemia, and undergoing chemotherapy. There was no exclusion due to age, gender, educational level, or socioeconomic status, since the purpose was to explore experiences and this required including all patients with the same experience, but with different rationalities and subjectivities.

Eight participants were selected using a purposive sampling. Data were gathered through in-depth interviews (two per interviewee)—at this stage, no new information emerged. Interviews started with a general question and moved carefully and gradually to the topic of sexuality. Respondents' privacy and confidentiality were protected. The interview received the approval of the Health Research Ethics Committee and the Scientific Committee of the healthcare institution.

The information was analyzed using the descriptive phenomenological method.[14] Likewise, the researchers used phenomenological reduction[14,15] to reflect on the need of suspending judgments about the phenomenon under study and tried to distance themselves from preconceived ideas in order to focus on experiences. In the first phase, information was gathered and the topics related to sexuality were tracked. In the second phase, an attempt was made to collect as much information as possible from different perspectives, and participants were invited to a second interview in order to compare emerging information with their experiences. In the third phase, an effort was made to grasp the essence and common structures of the sexuality experience as well as the relationships between them, and subtopics were defined. Finally, the meaning of the sexuality experience was analyzed in depth and the essence of the phenomenon of interest was revealed. The results were validated through triangulation by advisors throughout the analysis process; the field notes and feedback with the participants, through a second interview.

Results

The sample consisted of eight participants (five men and three women) between 22 and 69 years of age. All of them were hospitalized and their level of education ranged from elementary school to college (see Table 1). Three analysis topics emerged, which describe the experiences and meanings around sexuality.

Relationships are strengthened. Relationships with loved ones become stronger during the disease as a result of the visits in the hospital. They become more intense when patients cry and are moved by the unconditional support of their loved ones. The main family members involved in the process are children and partners. These relationships are of great value during disease recovery and treatment, especially when love and affection intensify. For the interviewee P1, the unconditional support of his family was really valuable. His voice chokes with emotion as he says that his loved ones left everything behind to be with him: *"I owe my recovery to the love of my family; they left their jobs to be with me... I can't even talk ... In this situation, you realize what you have. My wife, my children, my family are everything to me and they have been unconditional"* (P1-I1).

A diagnosis of leukemia may bring together and integrate the family thanks to the encounters in the hospital. From a handshake to a hug (something that had not happened before between two brothers), the attitudes change to open the way for better relationships: *"This has brought us closer because my family was not in contact, but now they're seeing each other and talking to each other. With my family,* [the relationship] *has improved a lot. For example, with my brother, we used to greet by shaking hands, but now he hugs me.* [My disease] *has been particularly shocking for him. He has investigated a lot about it ... It brought us closer. Everything changed because of the diagnosis. Wekeep in touch now"* (P6-I1).

Sexual desire is inhibited due to the disease. Desire, sexual satisfaction, and erotic expressions disappear while patients are hospitalized. Being diagnosed with leukemia changes life priorities and patients usually focus on their treatment and recovery. In this sense, the sex drive is inhibited and returns only when patients recover their normal life at home. Sexuality can be expressed at home through kisses, hugs, glances, and caresses: *"Regarding sexuality, when you recover from the disease, you understand that life goes on; but when you're diagnosed and undergoing treatment, you set it aside"* (P1-I2). *"I have another priority now: feeling better... I am focused on the disease, on my treatment, and on recovering. That's my priority"* (P2-I1).

Another aspect that limits sexual desire is isolation. The hospital protocol does not allow intimate contact; however, sexuality can be expressed in different ways: it is not just about genitality, but also about lovely words, attention, care, daily calls, hugs, and kisses: *"As you're hospitalized, you can't do anything. More than a limitation, I think this is a matter of health, isolation, and those things. Sex is not the only way of showing your partner that you love her. Here in the hospital, I worry about her, I call her every day, I hug her and kiss her, and I tell her lovely words. You have to win her heart every day. That's something that you can't take for granted"* (P4-I2).

Although age can be a barrier for sexual desire, this is not

Table 1. Demographic characteristics of the leukemia patients undergoing chemotherapy

Participant	Age	Sex	Education	Marital status
P1	69	Male	Bachelor's degree	Married
P2	22	Female	High school	Single
P3	34	Female	High school	Divorced
P4	28	Male	Elementary school (unfinished)	Domestic partnership
P5	65	Male	Three-year associate degree	Domestic partnership
P6	22	Male	Elementary school	Single
P7	22	Female	High school	Single
P8	37	Male	Bachelor's degree	Single

the case among the respondents, since they expect that, after the treatment, they can continue experiencing this aspect of their lives as part of their couple relationships: *"People think that you can no longer do it because of age, but this is something you can't ignore; it's part of the couple relationship"* (P1-I1).

As for erection and sexually active life, these are lost during hospitalization, as hospitalized patients do not think about sex nor feel desire. However, once they recover, they expect to reactivate their sex life, including erectile function: *"You don't think about it because there's no desire; what you don't desire doesn't come to your mind … I think that sex is not only erections … I expect to recover when the levels get to their point, continue having erections, and carry on my sex life that has been very active"* (P5-I1).

There is a need for information on sexuality. The interviewees perceived a lack of information on sexuality during their sickness and chemotherapy. They consider that this topic can cause embarrassment and that, perhaps, healthcare professionals believe that someone sick has no sexual desire. The fact that the patients did not ask for this information has to do with the cultural censorship and with the lack of knowledge about the effects of chemotherapy on fertility and sexual functioning. The patients consider information about sexuality important to make informed decisions and properly prevent or handle the effects of treatment: *"Honestly, I'd have felt embarrassed because of what they could think: 'I'm telling him he's sick and he's asking me about that'; I think I could've been more prepared if they had talked to me about that, about what could happen to me"* (P1-I2).

Thus, it is necessary to provide information about fertility and the current preservation methods to favor future procreation. These topics are not communicated before chemotherapy: *"They should provide more information on sexual reproduction because, for example, I didn't know that, before chemo, in the case of women or men [*sic*], you could do a process to preserve the eggs, so that later, when the treatment ends, if you want to have children, this could be easier"* (P2-GF).

Information on sexuality should address the importance of self-care and protecting the partner by using condom: *"This information is fundamental during treatment to know how to take care of yourself and protect your partner as well; I was using condom, but I didn't know how important that was; some may not use it, but, besides taking care of yourself, you should take care of your partner"* (P4-I1).

Discussion

The respondents' accounts describe a sexuality experience that goes beyond genitality and eroticism and involves communication and interaction with the family and the partner. For the participants, meeting with their families meant new forms of communication that resignified a language and an intense and different way of expressing themselves. In the case study by Nondeleu Arráez, the respondent denoted and appreciated the great support that he received from his family—especially wife and parents—and highlighted his partner's patience in the worst moments of the treatment; she became his main caregiver, his protector.[16]

Family members are perceived as committed and warm during the recovery process of their loved one. This is important because patients feel loved and supported in the most difficult moments of diagnosis and preventive isolation. The way that the family deals with the disease stages of one of its members favors family balance or homeostasis.[17] Robert et al. affirm that social support, such as that of the family, helps patients to cope actively and positively with difficult situations, which allows them to look for information, request professional help, and try to solve problems.[18] The study by Casas et al. states that patients with hematologic malignancies found in their families the main emotional support and motivation to fight the disease.[19] The social dimension should entail nursing care plans with actions that strengthen family bonds and foster loving and affection expressions. This, combined with knowledge on sexology, allows nursing professionals to offer better options to keep the family's ability to express feelings, try new ways of communication, and show interest in each other.

The leukemia patients undergoing chemotherapy expressed that their sexual appetite or desire was inhibited or that they did not feel sex drive; they justified this by mentioning their health condition, hospitalization, and isolation. The study by Gaviria et al. reports that most of the male patients accepted the changes, including sexual desire absence, and normalized them, since they took them as part of the natural aging process.[20] The patients also expressed that desire renews easily at home, which underpins the idea that low sexual desire is manifested during hospitalization. Similarly, McGrath's study expresses that the effects of the disease and the treatment on the patients' sexuality ranged from having no problems with sexual desire to having a mild impact that eventually disappeared. Likewise, this study shows that not all patients with hematologic malignancies experience sexuality issues.[17]

Other respondents attribute sex drive reduction to aging, but they expect to continue enjoying this aspect with their partner after the treatment. By the same token, the study by Gilbert et al. reports that many patients claimed to have understood the changes in their sexuality and accepted them as part of the natural aging process. The patients expected to carry on enjoying sexual activity in their old years through other forms, such as touch and tenderness.[21]

The present study shows that patients are concerned about their partner's satisfaction and their erectile function. The study by Álvarez et al. found that the patients with testicular cancer who underwent chemotherapy had no alterations in their erectile function and sexual desire.[22] The study by Gilbert et al. explains that the relationship status and the partner's support played a major role in the adaptation to sexuality-related physiological and psychological changes experienced after treatment.[21] The way that the partner supports and understands sexual changes should also be considered in the care plans for leukemia patients, in order to offer them different strategies to improve their couple relationship, including acceptance, support, and exploration of other forms of expressing physical affection.[17]

The interviewees manifested that they did not receive information about sexuality and fertility; however, they did not request it either because they lacked knowledge on the treatment consequences or because they considered this to be a very intimate and culturally unspeakable matter. The scarce information on sexuality also appears in the studies by Pereira and Schattman[23] and Camacho and Reyes,[24] which point out that

many patients are not aware of the possible changes in their sexual function or fertility, and that all the fertility preservation modalities remain underused. Even after cancer treatment, many patients still have unmet needs for information on how to recover their sexual function and fertility.

The participants say that they feel ashamed to talk about sexuality because it is a taboo and prefer that healthcare professionals take the initiative and inform them on that matter. This very concept of taboo was addressed by McGrath, who analyzed its impact on sexuality after the diagnosis and treatment of a hematologic malignancy; he states that the participants manifested the taboo nature of sexuality and the lack of information on the subject.[17] The study by Souza de Santana et al. indicates that healthcare professionals, by acts of either commission or omission, reinforce the misconceptions of sex as something detrimental to health.[25]

The classical care of cancer patients is focused on the effects of therapies, which downplays the importance of educating on sexuality and hinders proper advice on the options to preserve fertility.[26] In addition, there is this belief that sexual activity is not important for patients with cancer and their partners; as the disease puts patients' lives in danger, it is assumed that they place this concern before sexuality. However, it is a fact that they are concerned about their sexuality.[22] Furthermore, Moore et al. show that nurses neglect the sexuality area.[27]

Healthcare staff should acknowledge that sexuality needs to be included in care plans and consider the possibility to establish standards or protocols regarding sexuality, which be known by all the healthcare workers. Similarly, Katz proposes that the healthcare team in charge of cancer patients should be prepared to assess the difficulties concerning their sexuality and provide anticipated orientation related to the treatment and even to the reactivation of sex life.[4]

Conclusions

Sexuality experience of leukemia patients undergoing chemotherapy, in general, should be understood as the expression of tenderness feelings in an interpersonal relationship and should not be limited to genitality. Such experience is a permanent expression of love, harmony, and interest in the other, in which there is constant communication of attitudes, feelings, and emotions during hospitalization, isolation, and recovery at home.

In leukemia patients undergoing chemotherapy, the sexual appetite or desire comes second as a result of their health condition, hospitalization, and isolation; however, eroticism and desire reactivate in the recovery stage at home. Understanding this experience introduces new alternatives for the healthcare staff to address patients' sexuality. The care provided in this respect should include comprehensive information on eroticism, sexual desire, and other forms of sexual satisfaction.

Nursing professionals should take on the commitment to lead processes of humane care and should understand and recognize that hospitalized leukemia patients undergoing chemotherapy need, besides specialized care, to address their sexual needs. Information and communication on sexuality emerge as a highly significant need of the respondents and, in consequence, nurses should incorporate them in their care interventions, as they are closer to patients and their family.

References

1. Ortega MA, Osnaya ML, Barrientos JV. Leucemia linfoblástica aguda. Med Int Mex 2007;23:26-33.
2. Colombia. Ministerio de Salud y Protección Social. Guía de práctica para la detección, [el] tratamiento y [el] seguimiento de leucemias linfoblástica y mieloide en población mayor de 18 años. Bogotá: El Ministerio; 2017. Disponible en http://gpc.minsalud.gov.co/gpc_sites/Repositorio/ Conv_563/GPC_Leucemia_Mayores_18a%C3% B1os/GPC_Leucemias.pdf [acceso: 17/04/2018].
3. Ferreiro J, García JL, Barceló R, Rubio I. Quimioterapia: efectos secundarios. Gac Médica Bilbao 2003;100(2):69-74.
4. Katz A. The sounds of silence: sexuality information for cancer patients. J Clin Oncol 2005; 23(1):238-241.
5. López E, González E. Sexualidad y cáncer: toxicidad y tratamientos de soporte. Oncología 2005; 28(3):58-63. Disponible en http://scielo.isciii.es/ scielo.php?script=sci_arttext&pid=S037848352005 000300010 [acceso: 03/09/2018].
6. Pino Navarro CE. Disfunción sexual en pacientes con cáncer. Méd UIS 2010; 23(2):126-133.
7. López Ramírez E, González Flores E. Sexualidad y cáncer: toxidicidad y tratamientos de soporte. Oncol Barc 2005;28(3):58-63.
8. Zittoun R, Suciu S, Watson M, Solbu G, et al. Quality of life in patients with acute myelogenous leukemia in prolonged first complete remission after bone marrow transplantation (allogeneic or autologous) or chemotherapy: a cross-sectional study of the EORTC-GIMEMA AML 8A trial. Bone Marrow Transplant 1997;20(4):307-315.
9. Hordern AJ, Street AF. Communicating about patient sexuality and intimacy after cancer: mismatched expectations and unmet needs. Med J Aust 2007; 186(5):224-227.
10. Flynn KE, Reese JB, Jeffery DD, Abernethy AP, et al. Patient experiences with communication about sex during and after treatment for cancer. Psychooncology 2012; 21(6):594-601.
11. Olsson C, Berglund AL, Larsson M, Athlin E. Patient's sexuality - a neglected area of cancer nursing? Eur J Oncol Nurs 2012;16(4):426-431.
12. Jonker-Pool G, Hoekstra HJ, van Imhoff GW, Sonneveld DJ, et al. Male sexuality after cancer treatment - needs for information and support: testicular cancer compared to malignant lymphoma. Patient Educ Couns 2004; 52(2):143-150.
13. Schover LR, van der Kaaij M, van Dorst E, Creutzberg C, et al. Sexual dysfunction and infertility as late effects of cancer treatment. Eur J Cancer Suppl 2014; 12(1):41-53.
14. Ray MA. La riqueza de la fenomenología: preocupaciones filosóficas, teóricas y metodológicas. En: Morse JM (editora). Asuntos críticos en los métodos de investigación cualitativa. Medellín: Universidad de Antioquia, 2003:139-159.

15. Todres L, Holloway I. Investigación fenomenológica. En: Gerrish K, Lacey A (editores). Investigación en enfermería. Madrid: McGraw-Hill Interamericana, 2008 (5ta ed.): 224-237.
16. Nondedeu Arráez D. Cambios en el rol social del paciente oncohematológico: un estudio de caso. Index de Enfermería 2011; 20(3):165-168. Disponible en http://scielo.isciii.es/scielo.php?script=sci_ arttext&pid=S1132-12962011000200006 [acceso: 29/03/2020].
17. McGrath PD. The impact on sexuality after diagnosis and treatment for a hematologic malignancy: findings from Australia. Oncol Nurs Forum 2012; 39(6):595-600.
18. Robert V, Álvarez C, Valdivieso F. Psicosociología: un modelo de intervención y apoyo psicosocial. Rev Med Clin Condes 2013;24(4):677-684.
19. Casas Patarroyo CP, Otero de la Hoz DM, Mesa Melgarejo L del P, Carrillo AJ, et al. Prácticas de medicina tradicional y complementaria en pacientes con neoplasias hematológicas. Index de Enfermería 2017; 26(1-2):20-24. Disponible en http://scielo.isciii.es/scielo.php?script=sci_arttext&pid=S1132-12962017000100005&lng=es [acceso: 31/03/2020].
20. Gaviria AM, Vinaccia S, Riveros MF, Quiceno JM. Calidad de vida relacionada con la salud, afrontamiento del estrés y emociones negativas en pacientes con cáncer en tratamiento quimioterapéutico. Psicología desde el Caribe 2007;(20):50-75.
21. Gilbert E, Ussher JM, Perz J, Wong WK, et al. Men's experiences of sexuality after cancer: a material discursive intra-psychic approach. Cult Health Sex 2013;15(8):881-895.
22. Álvarez Puga MB, López González O, Álvarez Gallardo AM. ¿Afecta a la sexualidad del hombre padecer un tumor testicular? Paraninfo Digital 2014;8(20). Disponible en http://www.index-f.com/para/n20/278.php [acceso: 31/03/2020].
23. Pereira N, Schattman GL. Fertility preservation and sexual health after cancer therapy. J Oncol Pract 2017;13(10):643-651.
24. Camacho ME, Reyes-Ortiz CA. Sexual dysfunction in the elderly: age or disease? Int J Impot Res 2005;17Suppl1:S52-56.
25. Souza de Santana Carvalho E, Santos Paiva M, Casado Aparício E. El sexo es bueno, pero no puedo: representaciones de mujeres y hombres con heridas crónicas. Index de Enfermería 2013; 22(3):137-141. Disponible en http://scielo.isciii.es/ scielo.php?script=sci_arttext&pid=S1132-12962013 000200005 [acceso: 31/03/2020].
26. Scarella Chamy A, Díaz-García C, Herraiz S, Kliemchen Rodrigues J. Fertility preservation in the oncology patient. Medwave 2017;17(9):e7090.
27. Moore A, Higgins A, Sharek D. Barriers and facilitators for oncology nurses discussing sexual issues with men diagnosed with testicular cancer. Eur J Oncol Nurs 2013;17(4):416-422.