IV Simposio Cáncer de Pulmón en Mujeres

Madrid, 25 de febrero de 2016

ASPECTOS PSICOSOCIALES

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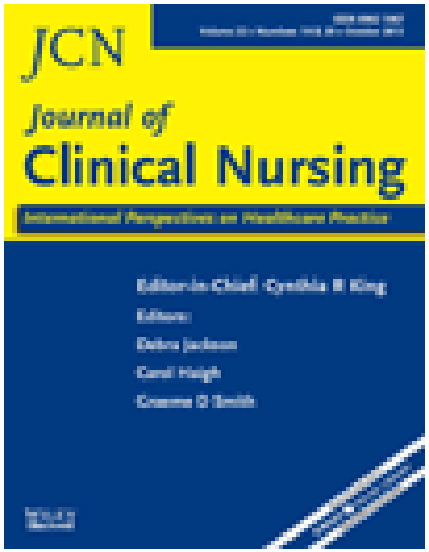
Hospital de Terrassa y Hospital Parc Taulí de Sabadell

Les voy a hablar de….

1. Evidencia científica que justifica el programa «Círculos»
2. «Círculos»:
   a) Antecedentes
   b) Estrategias y Objetivos
   c) Análisis de Resultados
   d) Evaluación



- «Los familiares juegan un importante papel proporcionando soporte social y emocinal a los pacientes con cáncer»

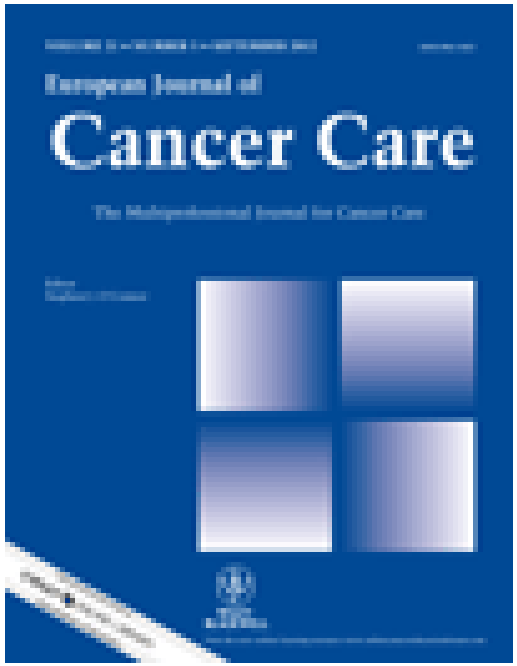
Bee PE, Barnes P, Luker KA. A systematic review of informal caregivers' needs in providing home-based end-of-life care to people with cancer. *J Clin Nurs.* 2009;18:1379-1393.

- Los familiares son un componente importante en el mantenimiento y la mejora de la calidad de vida de los pacientes con cáncer

Cancer. 2015 Jan 1;121(1):150-8. doi: 10.1002/cncr.29009. Epub 2014 Sep 10.

Dyadic psychosocial intervention for advanced lung cancer patients and their family caregivers: results of a randomized pilot trial.

Badr H[1], Smith CB, Goldstein NE, Gomez JE, Redd WH.



- «Aunque la preocupación relacionada con los síntomas físicos es menor en pacientes con cáncer de pulmón recién diagnosticados, ésta es más frecuentemente atendida que los asuntos psicosociales»

Hill KM, Amir Z, Muers MF, Round CE. Do newly diagnosed lung cancer patients feel their concerns are being meet? Eur J Cancer Care 2003; 12:35-45

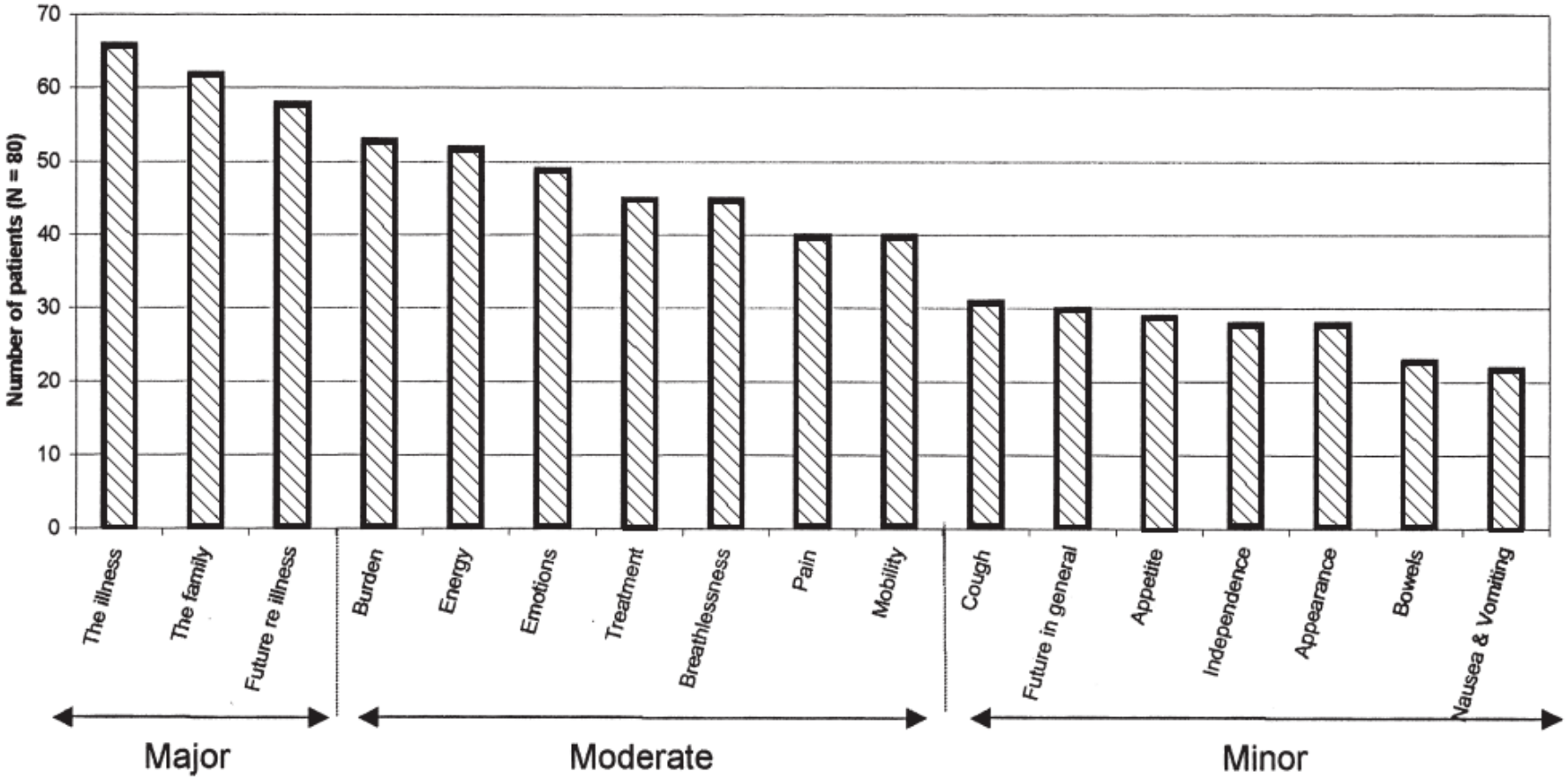


Figure 2. Categories and levels of concern.

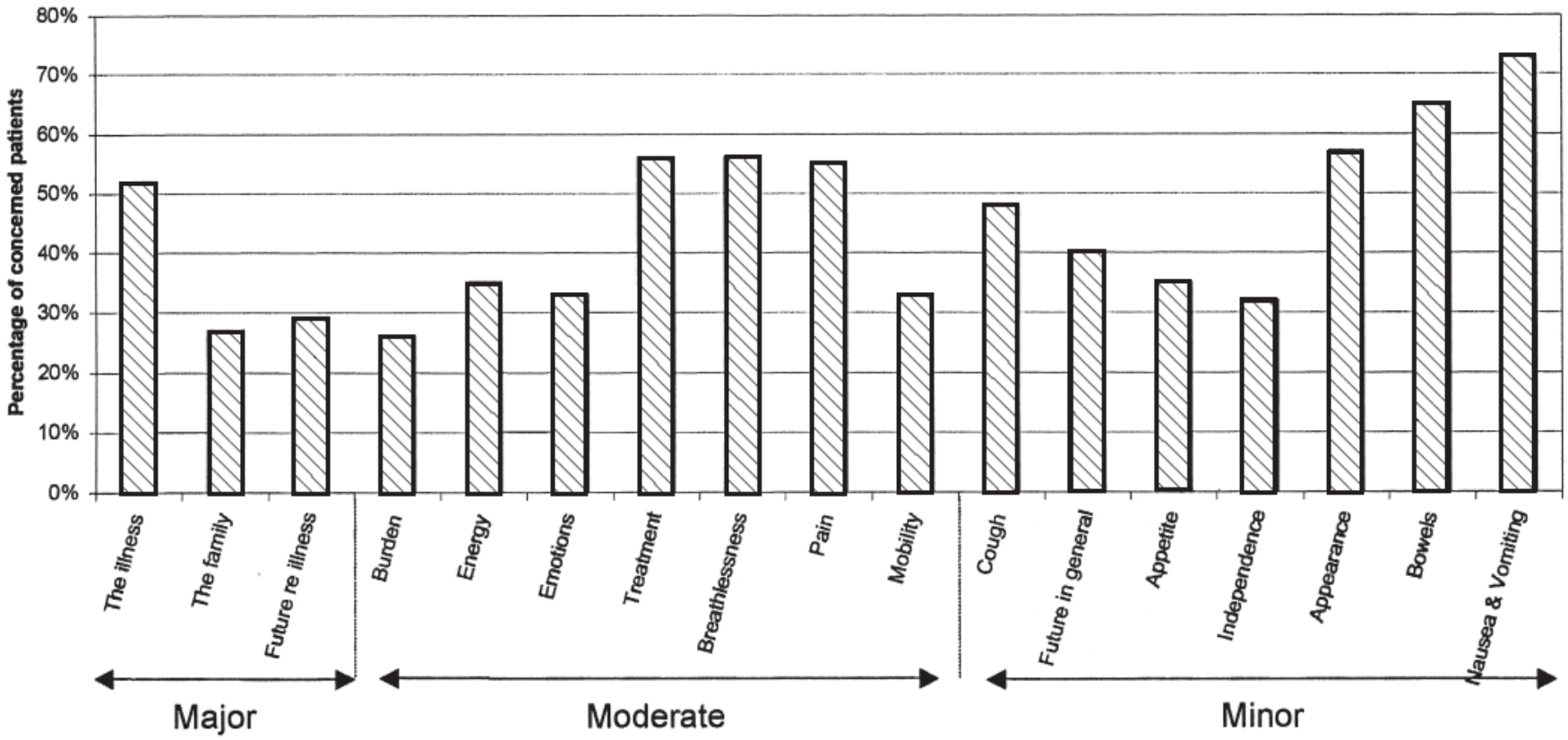


Figure 3. How patients reported their concerns were addressed by the Healthcare Team.

APPENDIX 1. THE CONCERNS CHECKLIST

We would like to know the different concerns about your illness and treatment that may have been worrying for you over the last week. There are no right or wrong answers. Your answers will be treated confidentially.
Please answer all the questions.

Have you worried about…

1. The illness itself (what it is, is it better, etc.…)

Not a worry □
Slightly worried □
Moderately worried □
Very worried □
Extremely worried □

If you have been worried – has any member of the care team talked to you about this?
Yes □ No □

2. Pain (whether you have any or are concerned about it)

Not a worry □
Slightly worried □
Moderately worried □
Very worried □
Extremely worried □

If you have been worried – has any member of the care team talked to you about this?
Yes □ No □

3. Your mobility

Not a worry □
Slightly worried □
Moderately worried □
Very worried □
Extremely worried □

If you have been worried – has any member of the care team talked to you about this?
Yes □ No □

4. Appetite and weight loss

Not a worry □
Slightly worried □
Moderately worried □
Very worried □
Extremely worried □

If you have been worried – has any member of the care team talked to you about this?
Yes □ No □

5. Your energy level (or weakness)

Not a worry □
Slightly worried □
Moderately worried □
Very worried □
Extremely worried □

If you have been worried – has any member of the care team talked to you about this?
Yes □ No □

6. Treatment of your illness

Not a worry □
Slightly worried □
Moderately worried □
Very worried □
Extremely worried □

If you have been worried – has any member of th team talked to you about this?
Yes □ No □

7. Breathlessness

Not a worry □
Slightly worried □
Moderately worried □
Very worried □
Extremely worried □

If you have been worried – has any member of th team talked to you about this?
Yes □ No □

8. Nausea and vomiting

Not a worry □
Slightly worried □
Moderately worried □
Very worried □
Extremely worried □

If you have been worried – has any member of th team talked to you about this?
Yes □ No □

9. The future (relating to your illness)

Not a worry □
Slightly worried □
Moderately worried □
Very worried □
Extremely worried □

If you have been worried – has any member of the care team talked to you about this?
Yes □ No □

10. Your independence (in the house, daily activities, socially)

Not a worry □
Slightly worried □
Moderately worried □
Very worried □
Extremely worried □

If you have been worried – has any member of the care team talked to you about this?
Yes □ No □

11. Your emotions

Not a worry □
Slightly worried □
Moderately worried □
Very worried □
Extremely worried □

If you have been worried – has any member of the care team talked to you about this?
Yes □ No □

12. Your family (and their emotions)

Not a worry □
Slightly worried □
Moderately worried □
Very worried □
Extremely worried □

If you have been worried – has any member of the care team talked to you about this?
Yes □ No □

13. Cough

Not a worry □
Slightly worried □
Moderately worried □
Very worried □
Extremely worried □

If you have been worried – has any member of the care team talked to you about this?
Yes □ No □

14. The future (not relating to your illness)

Not a worry □
Slightly worried □

If you have been worried – has any member of th team talked to you about this?
Yes □ No □

15. Feeling a burden

Not a worry □
Slightly worried □
Moderately worried □
Very worried □
Extremely worried □

If you have been worried – has any member of th team talked to you about this?
Yes □ No □

16. Bowels

Not a worry □
Slightly worried □
Moderately worried □
Very worried □
Extremely worried □

If you have been worried – has any member of th team talked to you about this?
Yes □ No □

17. Your appearance

Not a worry □
Slightly worried □
Moderately worried □
Very worried □
Extremely worried □

If you have been worried – has any member of th team talked to you about this?
Yes □ No □

18. Any other concerns

Not a worry □
Slightly worried □
Moderately worried □
Very worried □
Extremely worried □

If you have been worried – has any member of th team talked to you about this?
Yes □ No □

11. Hudson P, Remedios C, Zordan R, et al. Guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients. *J Palliat Med*. 2012;15:696-702.
12. Bakas T, Lewis RR, Parsons JE. Caregiving tasks among family caregivers of patients with lung cancer. *Oncol Nurs Forum*. 2001;28:847-854.
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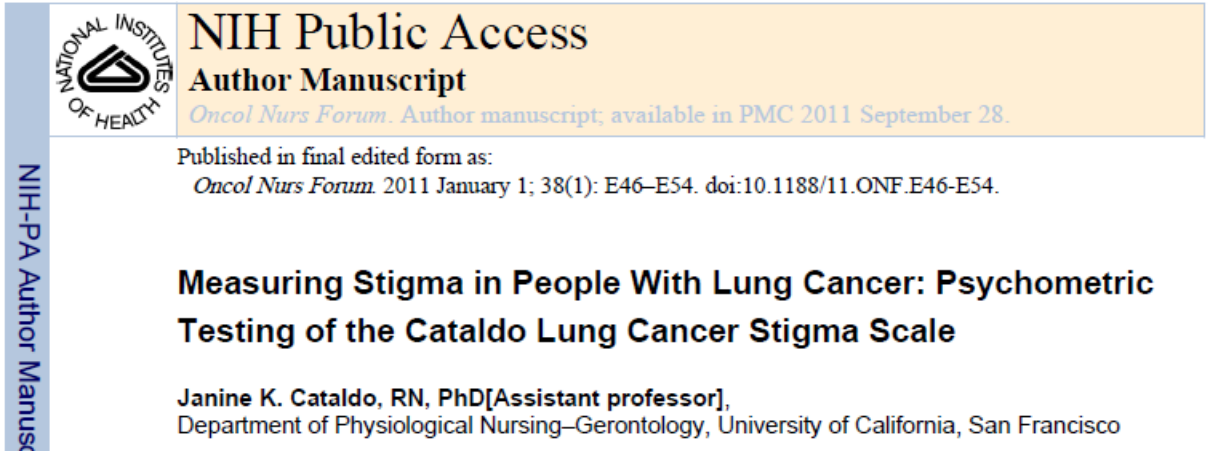
14. Carmack Taylor CL, Badr H, Lee L, et al. Lung cancer patients and their spouses: psychological and relationship functioning within 1 month of treatment initiation. *Ann Behav Med*. 2008;36:129-140.
15. Cooper ET. A pilot study on the effects of the diagnosis of lung cancer on family relationships. *Cancer Nurs*. 1984: 301-308.

- «... el soporte que se da a las familias es frecuentemente insuficiente»
- «... las necesidades no cubiertas afectan a las relaciones familiares»
- ... tanto pacientes como familiares expresan una disminución de su grado de intimidad y aumento de los conflictos ...»

Factores asociados al estigma percibido por pacientes con cáncer de pulmón

- La vergüenza
- El aislamiento social
- La discriminación
- El fumar



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Measuring Stigma in People With Lung Cancer: Psychometric Testing of the Cataldo Lung Cancer Stigma Scale

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Curr Oncol, Vol. 21, pp. e718-722; doi: http://dx.doi.org/10.3747/co.21.2034

SHORT COMMUNICATION

Shame, guilt, and communication in lung cancer patients and their partners

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ABSTRACT

Lung cancer patients report the highest distress levels of all cancer groups. In addition to poor prognosis, the self-blame and stigma associated with smoking might partially account for that distress and prevent patients from requesting help and communicating with their partners. The present study used innovative methods to investigate potential links of shame and guilt in lung cancer recovery with distress and marital adjustment. A specific emphasis was an examination of the impact of shame on partner communication. Lung cancer patients ($n = 8$) and their partners ($n = 8$) completed questionnaires and interviews that were videotaped. We report descriptive statistics and Spearman correlations between shame and guilt, relationship talk, marital satisfaction, distress, and smoking status. We coded the interviews for nonverbal expressions of shame.

Greater self-reported shame was associated with decreased relationship-talk frequency and marital satisfaction, and with increased depression and smoking behaviour. Nonverbal shame behaviour also correlated with higher depression and increased smoking behaviour. Guilt results were more mixed. More recent smoking behaviour also correlated with higher depression. At a time when lung cancer patients often do not request help for distress, possibly because of shame, our preliminary study suggests that shame can also disrupt important partner relationships and might prevent patients from disclosing to physicians their need for psychosocial intervention and might increase their social isolation. Even if patients cannot verbally disclose their distress, nonverbal cues could potentially give clinicians an opportunity to intervene.

KEY WORDS

Lung cancer, shame, guilt, communication, relationships, smoking

1. INTRODUCTION

Compared with other cancer patients, patients with lung cancer report greater distress[1,2] and more unmet needs[3]. Greater distress could result from poor prognosis[2], feelings of responsibility for the cancer[4], or the impact of stigma from lung cancer's association with smoking[5].

Shame is a prototypical response to devaluation of the social self[6] and leads to hiding and nondisclosure because of overwhelming feelings of low self-worth. Higher levels of shame can increase depression[7] and levels of cortisol and proinflammatory cytokines[8]. Guilt can be an uncomfortable emotion, but it can often be resolved; in contrast, shame occurs "when a core aspect of the self is judged as defective, inferior or inadequate"[8] and can be extremely painful[9].

Clients who report not disclosing salient topics in psychotherapy also report less improvement and most often cite shame as the reason for nondisclosure[10]. Nondisclosure follows directly from shame; shame involves an urge to hide from others because of negative self-evaluation[9] and can potentially include nondisclosure to cancer physicians and partners about important needs. In contrast to nondisclosure, engagement in open, supportive communication increases marital satisfaction and reduces distress in cancer patients[11,12]. Because communication helps patients adapt to cancer, couples that communicate effectively, with more discussion about their relationship ("relationship talk"), can experience greater marital adjustment and less distress throughout the illness[12,13]. However, compared with other cancer patients, patients with lung cancer can experience more problems with communication[14].

In this population with high distress, poor prognosis, and smoking stigma leading to shame, we posited that partnered relationships provide a source of support that is more important for them than for other cancer patient groups. If shame disrupts the relationship, lung cancer patients will have

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- «Findings indicate that increased self-reported Shame is associated with lower levels of couples' communication and marital satisfactions and with greater distress.»

círculos

Programa de **(in)formación**

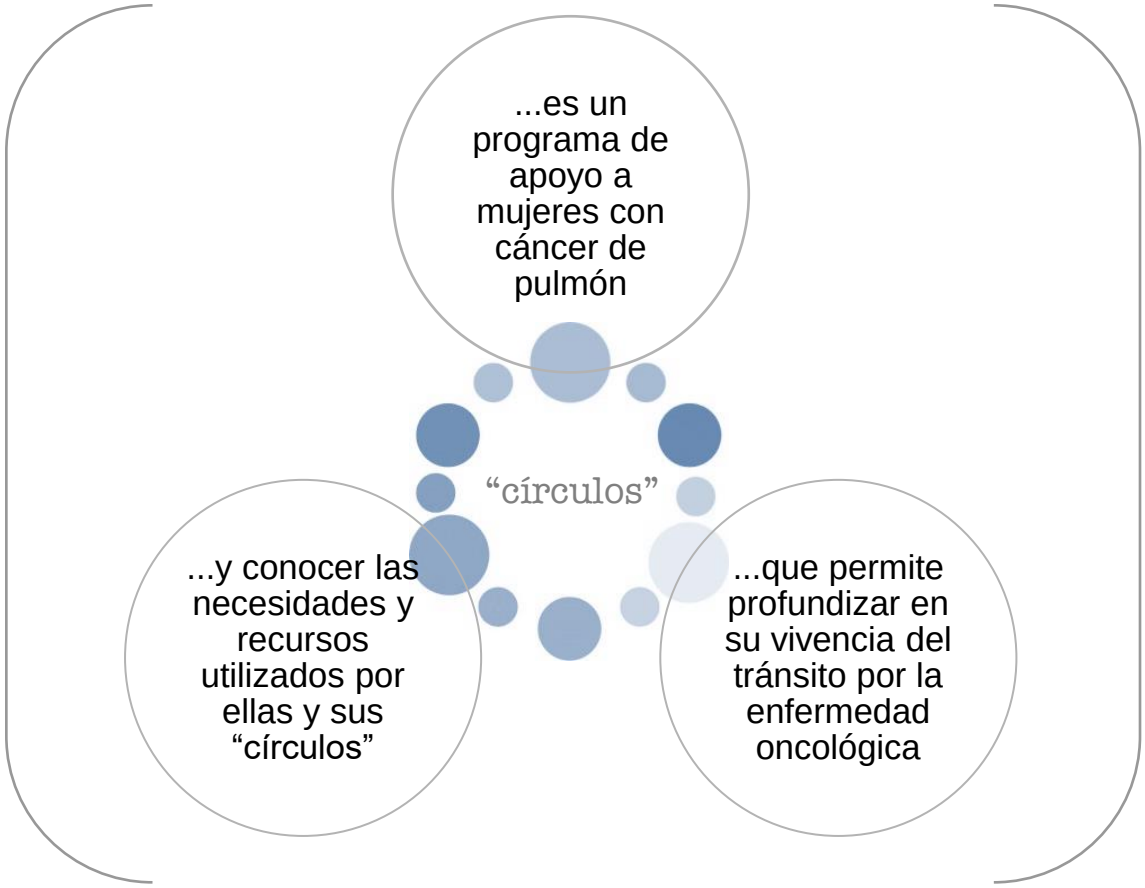
Para **mujeres** con cáncer de pulmón

Fundación
María José Jove

ICAPEM

esencias de “círculos”

programa de (in)formación para mujeres con cáncer de pulmón



equipo

recursos y activos profesionales

Rosario García Campelo

Oncóloga médica especialista en Cáncer Pulmón.
Directora Científica ICAPEM en proyecto “círculos”

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Yolanda Isabal

Fundadora y Directora de TACTICS. Coach facilitadora de procesos de desarrollo personal y organizativo.

Presentación del proyecto

círculos

centros implicados

centro	ciudad	Oncólogo médico	nº pacientes
Hospital Universitario A Coruña	A Coruña	Dra. Rosario García Campelo	4
Complexo Hospitalario Universitario de Vigo	Vigo	Dr. Martín Lázaro Quintela	1
Hospital Universitario Santiago	Santiago Compostela	Dra. Francisca Vázquez Rivera	3
Hospital Universitario Lucus Agusti	Lugo	Dr. Sergio Vázquez Estevez	1
Hospital Arquitecto Marcice	Ferrol	Dr. Francisco Javier Alonso	-
Complexo Hospitalario Universitario de Ourense	Ourense	Dr. Fivida/Dra. Mª Areses	2
Hospital Pontevedra	Pontevedra	Dr. Luis León	-
		Total	**11**

estrategias y objetivos de “círculos”

programa de (in)formación para mujeres con cáncer de pulmón

objetivos
estrategia investigadora

círculo mujeres

A. Conocer las necesidades y recursos de las participantes en su tránsito por la enfermedad oncológica.

A.1. Profundizar en el conocimiento de las necesidades.

A.2. Profundizar en el conocimiento de los recursos de afrontamiento.

A.3. Compartir y poner en común necesidades y recursos.

círculo íntimo (familiares)

B. Conocer las necesidades y recursos de las participantes en su tránsito por la enfermedad oncológica.

B.1. Profundizar en el conocimiento de las necesidades.

B.2. Profundizar en el conocimiento de los recursos de afrontamiento.

B.3. Compartir y poner en común necesidades y recursos.

estrategias y objetivos de “círculos”

programa de (in)formación para mujeres con cáncer de pulmón

objetivos
estrategia interventiva

círculo mujeres.

C. Activar y desarrollar nuevas estrategias de apoyo y afrontamiento considerando las necesidades identificadas y la literatura consultada.

C.1. Activar y desarrollar apoyo emocional.

C.2. Activar y desarrollar apoyo informacional.

C.3. Activar y desarrollar apoyo instrumental.

círculo íntimo (familiares).

D. Conocer las necesidades y recursos de las participantes en su tránsito por la enfermedad oncológica.

D.1. Activar y desarrollar apoyo emocional.

D.2. Activar y desarrollar apoyo de información.

D.3. Activar y desarrollar apoyo instrumental.

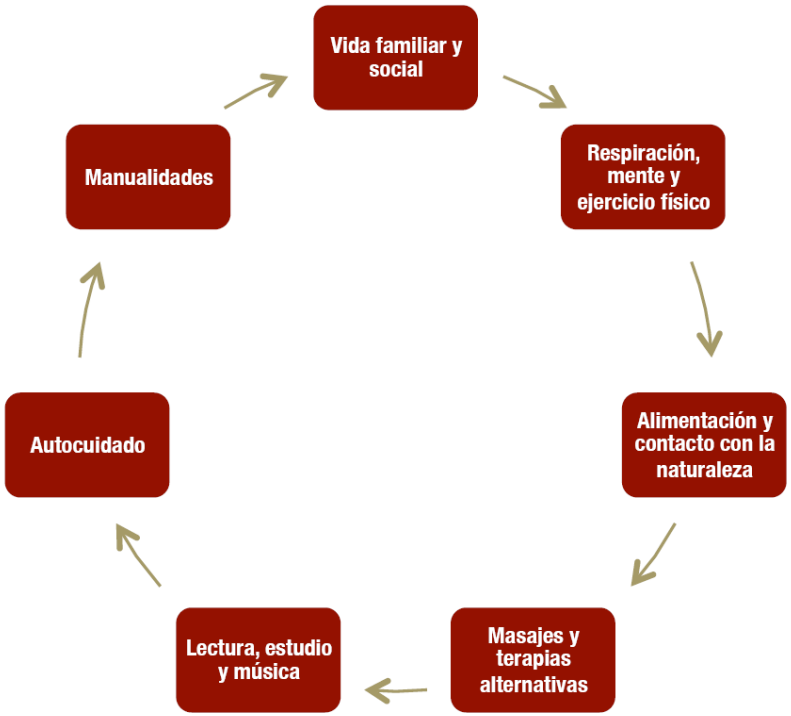
¿Qué esperan del círculo?

- Compartir experiencias e información con las demás participantes.
- Desplazar del foco de la enfermedad al foco de la vida.
- Compañía.
- Espiritualidad.
- Fuerza.
- Guía para saber qué hacer (psicología y medicinas alternativas).
- Cómo afrontar la soledad, en especial con la pareja.
- Ideas para el manejo de los hijos cuando se está sola.

¿Qué no esperan del círculo?

- No hablar del pasado.
- No centrarnos en la parte negativa de la enfermedad.
- No dramas.

MIS RECURSOS...
LO QUE ME FUNCIONA ES...
LA SEGURIDAD EN MI MISMA, MI AUTOESTIMA Y LAS GANAS DE DISFRUTAR LA VIDA
HAGO TODO LO QUE ME GUSTA, RECIBO A "TODOS" CON LOS BRAZOS ABIERTOS, SOLO NO ME CONSUELA LLORAR, SOLO QUIERO ESTAR BIEN, SI ME
CAMINO, COCINO QUE ME ENCANTA, HABLO CON TODOS, CURIOSEO EN INTERNET ME DISTRAIGO CON LA ALIMENTACIÓN, RIO CON MI FAMILIA
CUIDO MI JARDIN, Y SIEMPRE ME FALTAN HORAS. DESPUES ESTAN MIS AMIGOS, PERO LO QUE DIGO ARRIBA SON MIS RECURSOS MAS CERCANO
ATASCO EN EL DIA A DIA, REBUSCO Y SIEMPRE ENCUENTRO ALGO QUE ME ANIME. TENGO A MI ALREDEDOR TODO LO QUE NECESITO, INCLUYO PERSONAS Y COSAS. PERO MI MEJOR RECURSO ES HABLAR CON MI MADRE, ELLA SIEMPRE ME CONSUELA



Acciones que nos ayudan.

Vida familiar y social	• Ver bien a nuestros hijos y familiares. • Recibir a todos con los brazos abiertos. • Dar y recibir abrazos. • Reir con tu familia. • Hablar con nuestros familiares (madres, parejas, hermanos, hijos...). • Pasar ratos con los amigos. • Salir de casa a tomar café con los amigos. • Ocultar la enfermedad a algunos familiares (madres mayores). • Hacer cosas con los amigos íntimos. • Hablar con todos.Facebook. • Ir de compras. • Contratar ayuda externa (por ejemplo para las tareas del hogar y cotidianas).
Respiración, mente y ejercicio físico	• Pasear[1] y caminar. • Controlar la respiración en momentos de angustia o inseguridad. • Karate. • Chi Kung. • Gimnasia.

[1] Esta ha sido la acción más destacada por las participantes.

repercusión "círculos"

números de la experiencia piloto

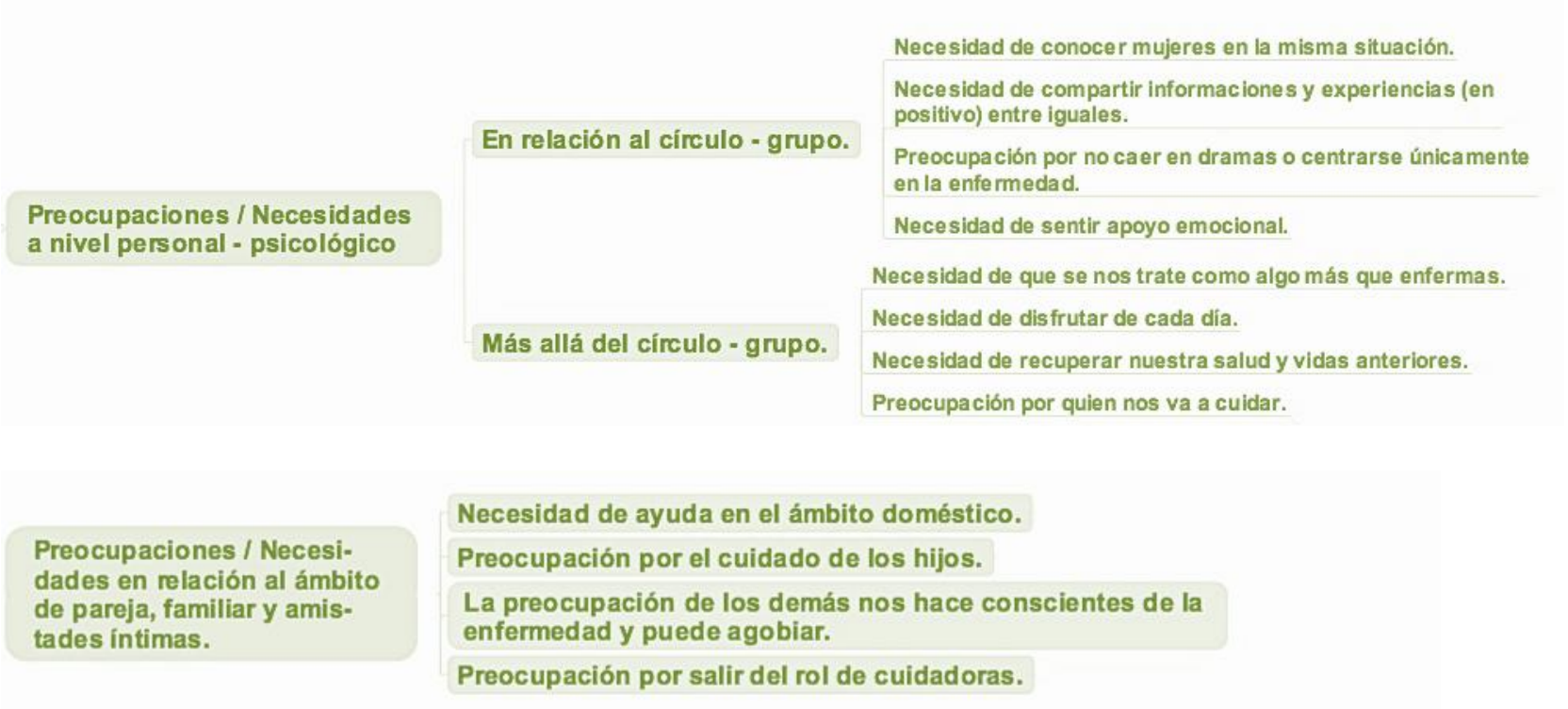
10	Mujeres diagnósticadas con cáncer de pulmón residentes en Galicia han partido en las sesiones.
5	Sesiones realizadas con el círculo de mujeres.
1	Sesión realizada con el círculo de familiares.
1	Sesión realizada con personas del entorno social.
22	Horas de trabajo directo en sesiones de apoyo a las mujeres.
6	Mujeres han asistido de media a las sesiones.
2	Bajas, una baja por fallecimiento y otra por desinterés con el programa.
11	Familiares y amigos/as han participado en el encuentro final.
10	Familias se han beneficiado indirectamente de los efectos de círculos.

análisis de resultados

y conclusiones

resultados investigación

círculo mujeres

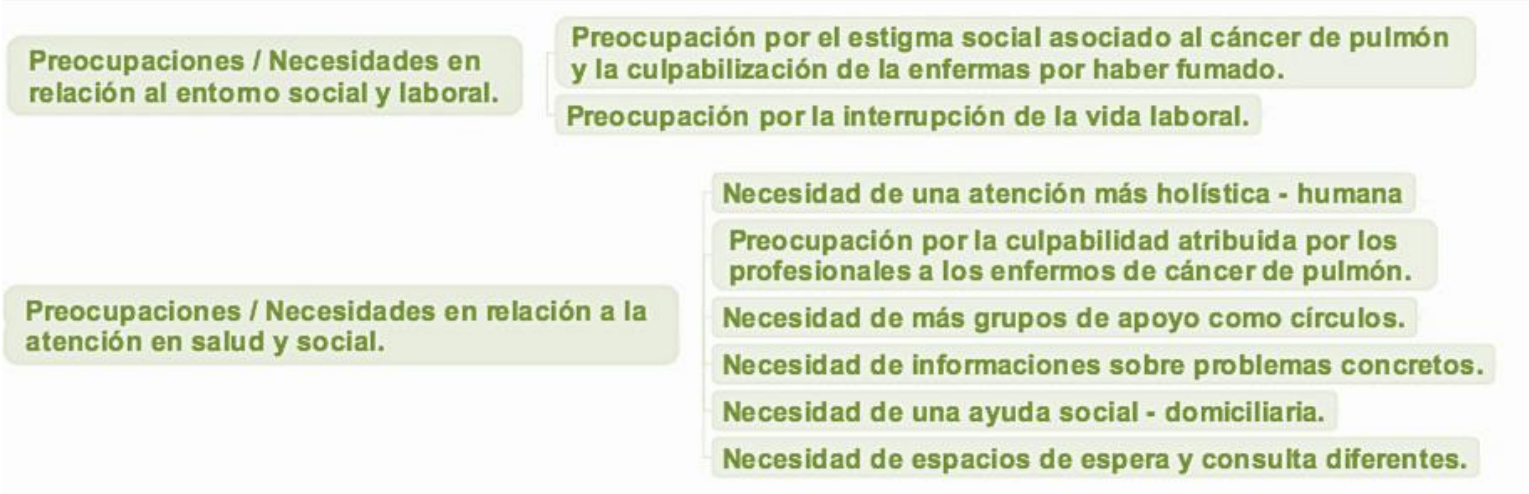


análisis de resultados

y conclusiones

resultados investigación

círculo mujeres

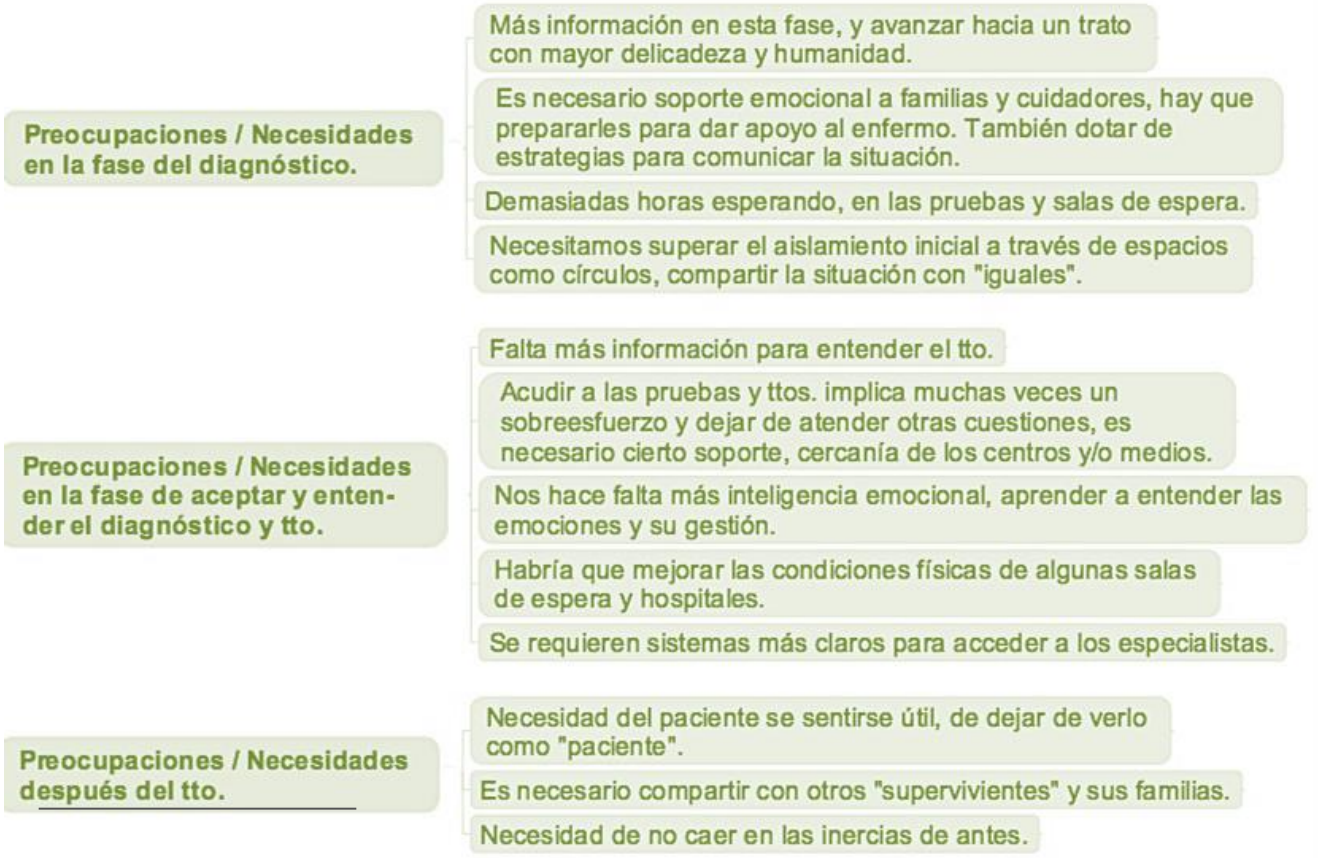


análisis de resultados

y conclusiones

resultados investigación

círculo familiares



análisis de resultados

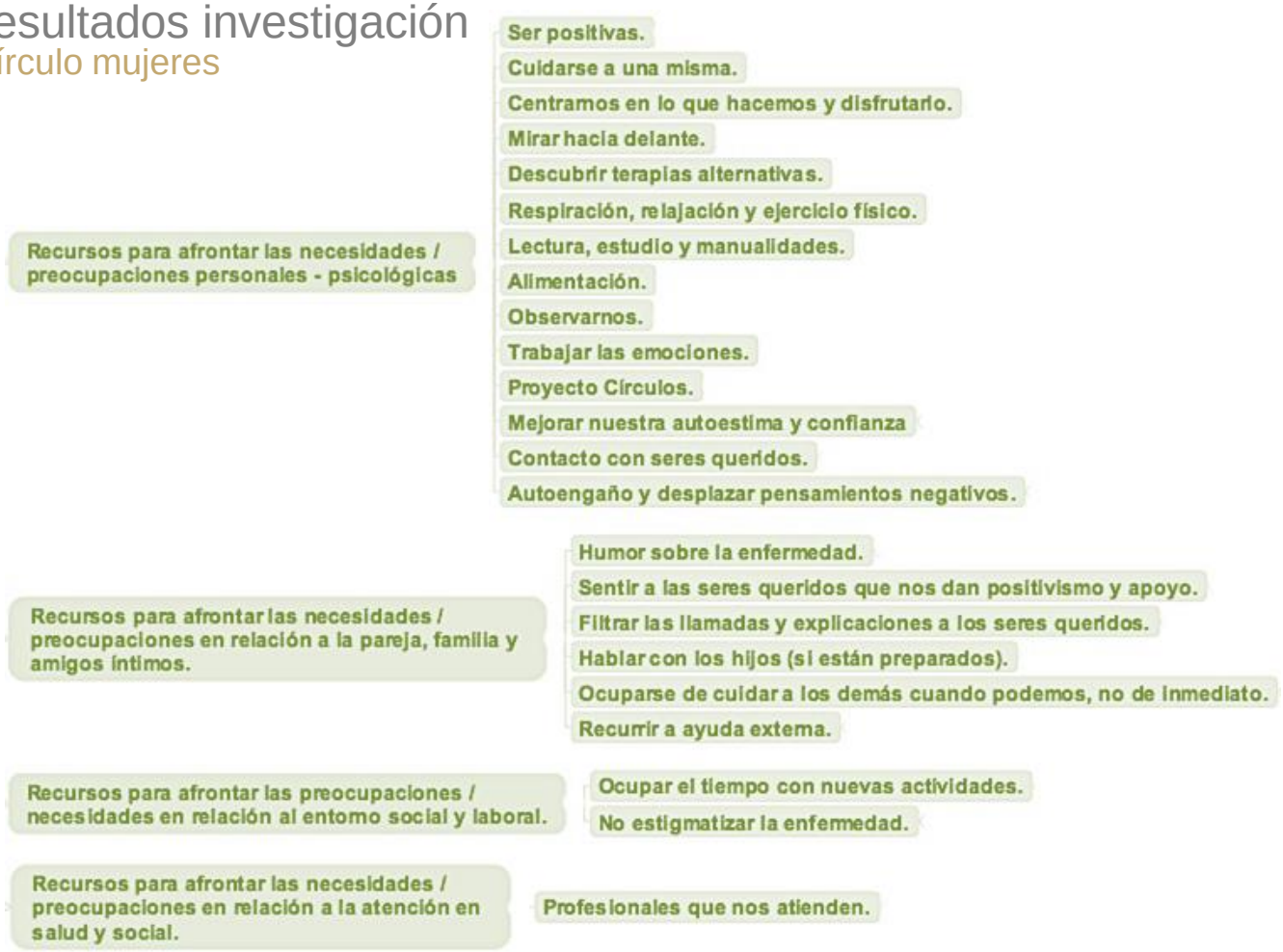
y conclusiones

análisis de resultados

y conclusiones

resultados investigación

círculo mujeres



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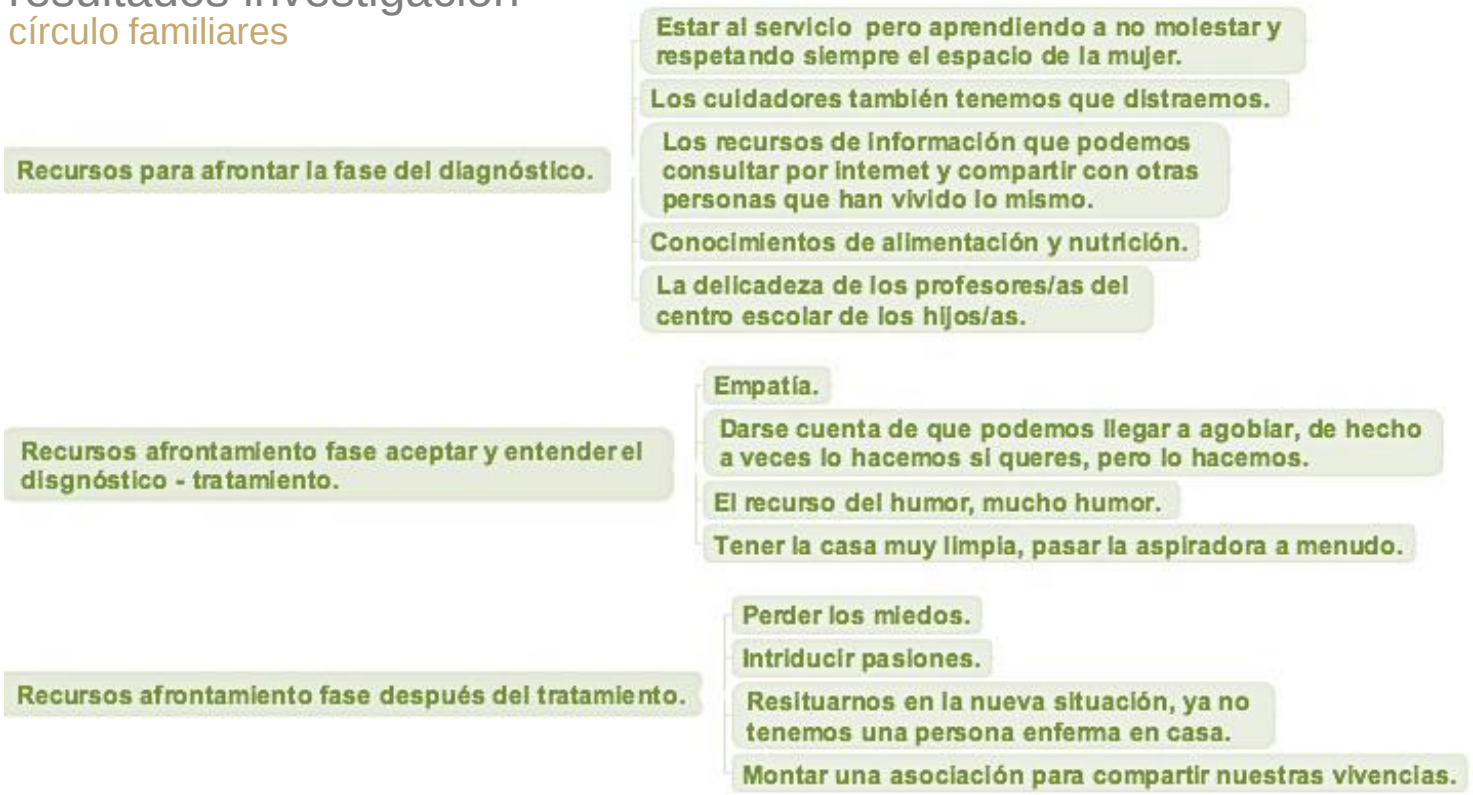
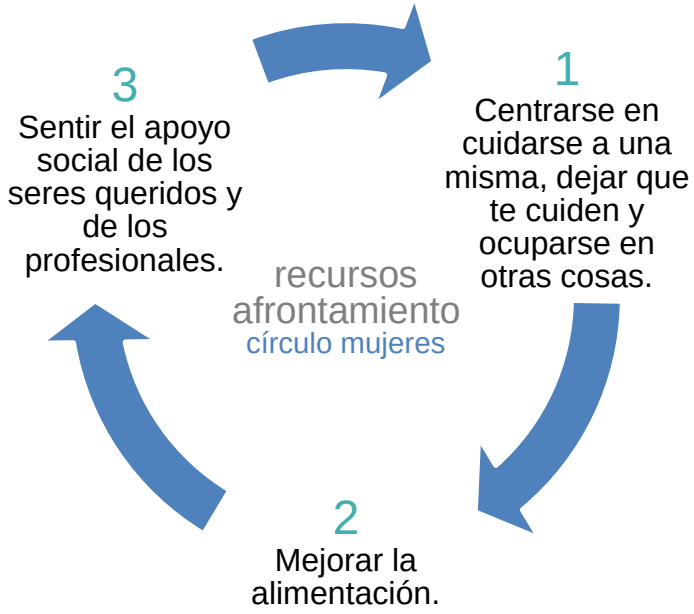
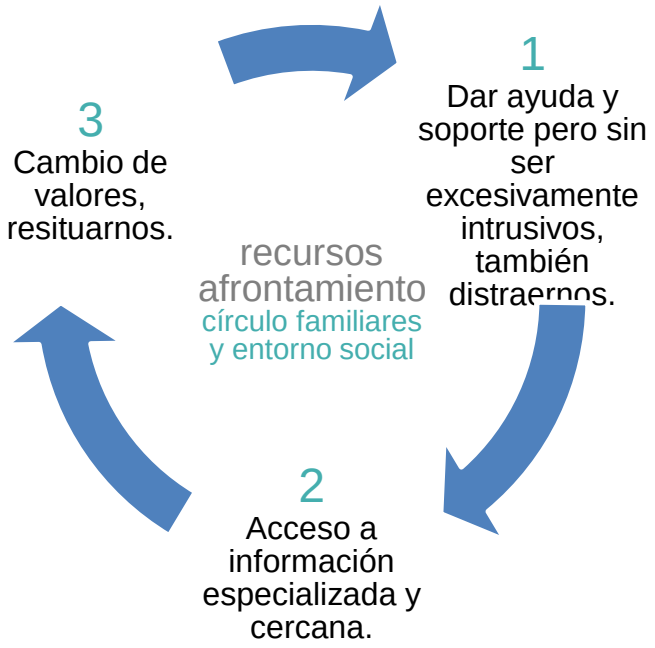
círculo familiares



análisis de resultados

y conclusiones



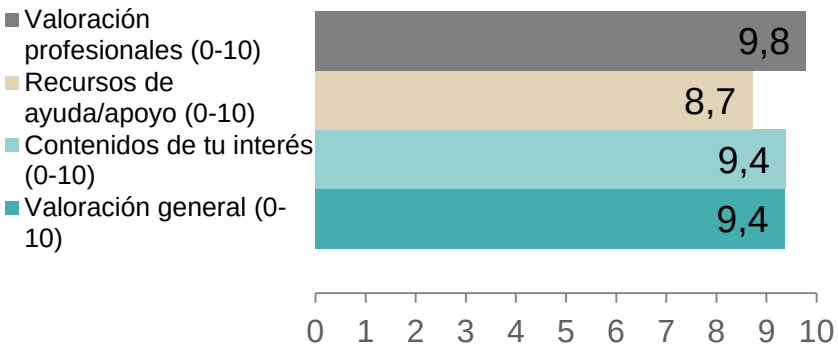


evaluación

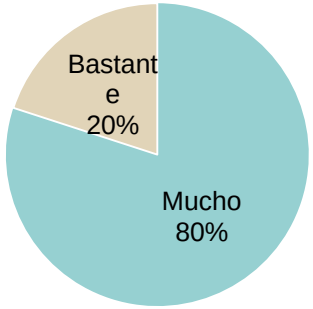
encuentro final en Santiago con círculos

círculo de mujeres (N=5)

Valora los siguientes aspectos del 0 al 10.



¿círculos ha cumplido con las expectativas iniciales que tenías?



¿qué hubieras mejorado de "círculos"?

- Más tiempo
- Conseguir que todas asistan a todas las sesiones
- Me ha gustado todo lo propuesto
- La frecuencia de las reuniones, más a menudo.

¿qué te gustó más de "círculos?

- El interés que generó
- Conocer a otras enfermas y hacer grupo, la fuerza que sentí.
- La complicidad y la ilusión
- El grupo que conformamos enfermos y profesionales

agradecimientos

participantes

Queremos agradecer a cada una de las mujeres que han hecho posible esta experiencia.
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