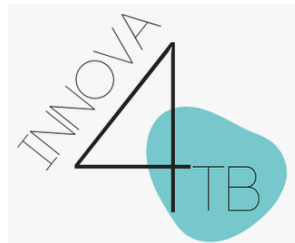


Photovoice: the vision of TB through the pictures of patients

Joan Pau Millet
Núria Forcada



What is Photovoice ?

Photovoice is a community-based participatory action research method that uses photography as a means for understanding and giving voice to the experiences of study participants. The resulting “photo novellas” have been used to support advocacy, and program planning for marginalized communities.



The Barcelona Project is born of a collaboration between Epidemiology Service from ASPB (Public Health Agency of Barcelona) and Serveis Clínic (TB Clínic in Catalonia) with Public Health of Toronto (that have a big experience with this research method)



- 1) To provide an opportunity for TB patients in Barcelona to record and share their day-to-day lives and experiences with tuberculosis through photos.
- 2) To help health professionals, the community, and other TB patients/families understand the lived experience of having TB in Barcelona from diverse perspectives and decrease stigma

Methods

Num. Participant patients	16
Starting enrollment date	April 2016
End date	August 2016
Inclusion criteria	➤ ≥ 18 years old ➤ inpatients at TB clinic (Serveis Clínic) ➤ under TB treatment ➤ Signed ICF ➤ able to use a camera ➤ not needing support due to mental health problems

Participants

Sites	Serveis Clínic (TB clínic)
Participants	. Varied patients profile in terms of gender, age and country of origin. . Personal interview. . Voluntary and anonymous participation if preferred.
Participation rules	. Unpublished photos taken by the participants . Reflect personal experience with TB . Maximum selection of 5-10 photos per person

Photovoice participants

Site (city)	Barcelona
Number	16
Gender	12 male, 4 female
Age range	18-63
Country of origin	Venezuela, Romania, Spain, Angola, Marruecos, Camerun, India, Pakistan, Algeria, Bangladesh and Bolivia.



- Enrique
- Suso
- Paulo
- Mehdi
- Salam
- Ahmed
- Sheran
- Isidro
- Anonymous

Results

Total number of photos (+text)	83
Topic developement	. Individual analysis of each researcher of all photos. .Organization in groups of pictures by topics/themes/subjects. . An explanatory text of every photo: translation in 4 languages (Eng/Fr/Sp/Cat)
Topics/themes/subjects (11)	- The impact of isolation - Coping mechanisms - Difficulties - A new beggining - Resilience - Physical experience - Positive thoughts - Things I miss - A stop in my life - Fight - Stigma

The impact of isolation



Le sentiment de l'isolation
Le sentiment qui a un isole
pour la raison de la
tuberculose c'est le même
d'un prisonnier la seul
différence c'est que le
malade sait qu'il va passer un
peu de temps et c'est fini,
mais le prisonnier ça devant
de son motif, mais le malade
est un prisonnier sans motif.

The feeling of isolation – The feeling I have when I was isolated with TB, is the same feeling as a prisoner in jail. The only difference is a prisoner has a reason but a TB patient is a prisoner with no reason.

El sentimiento de aislamiento – El sentimiento que tuve cuando estaba aislado con TB es el mismo sentimiento que un prisionero en una cárcel. La única diferencia es que un prisionero tiene una razón pero un paciente con tuberculosis es prisionero sin razón.
Mhedi Sabel

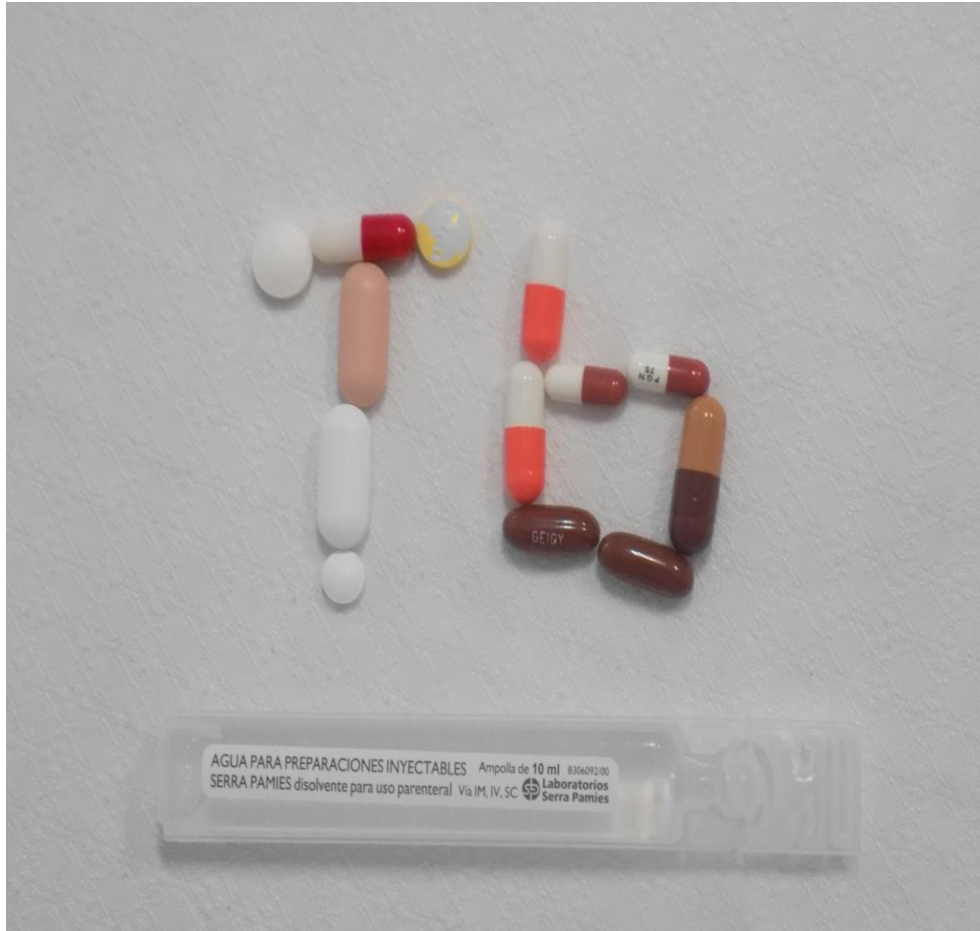
Coping Mechanisms



Music - Music is a way to keep my mind occupied so I don't always think about the disease

La Música – La Música es una manera para tener mi mente ocupada y no pensar siempre en la enfermedad.

Paulo



Día a Día...

Las pastillas serán tu meta diaria y es pensar que cada toma es una menos, pero cuando piensas en la cantidad de pastillas que han entrado a tu cuerpo por años...sientes muchas cosas.

Day by Day...

The pills will be your daily goal. You think every time you take the pill, it is one less but when you think of the number of pills that have entered your body for a year, you feel many things.

Enrique

A new beginning



Flower - I am waiting for the treatment to finish because there are a lot of beautiful things waiting for me

Flores – Estoy esperando el final de tratamiento porque hay muchas cosas bonitas esperándome

Paulo

A new beginning



Pienso que cuando acabe esto podré volver a mi vida....trabajar, empezar un negocio y buscar una buena chica.

I think when I finish this I will return to my life. Work, start a business, find a nice girl.

Sheran Babar



Cárcel - TB es como un castigo para mí. Tengo que luchar para recuperar.

Jail - TB is like a punishment for me. I have to fight to recover

Anonym



Todo Es Pasajero - Todo es temporal incluso el tratamiento de la TB. Todo pasa y consigues superarlo.

Everything will pass - Everything is temporary including the treatment of TB. It passes and you get through it.

Anonym

Things that I miss



Te Echo De Menos - El aislamiento, el riesgo de contagio, los efectos secundarios en cuanto tus sentimientos y emociones, son elementos que impiden el poder estar íntimamente con alguien.

I miss you - The isolation, the risk of infection, and the side effects in terms of your feelings and emotions, are elements that can prevent you to be intimate with someone.

Enrique



We need to keep fighting to overcome the disease.
Necesitamos continuar luchando para vencer la enfermedad.
Paulo



La vie non decente provoque ce genre de maladie: Pauvreté, Le manque d'alimentation, etc.

The non-decent life provokes this kind of illness. E.g. poverty, no food, etc.

La vida no decente provoca esta enfermedad. Por ejemplo – la pobreza, no comer, etc.

Anonym

International TB world Congress: The Union. Vancouver 2017
Barcelona world TB Day 2017
Nursing International Conference. Barcelona 2017
Spanish Thoracic and Pneumology Congress: Madrid 2017.
Social Media: Facebook, Twitter
Scientific Websites: Toronto PH, UITB,...
Educational materials.
Monographic book: available at:
Hall exhibitions: Public Health Agency of BCN, Serveis Clínic.....

A Picture Paints A Thousand Words: Facilitating the voice of individuals diagnosed with Tuberculosis (TB) in Toronto and Barcelona through Photovoice
Amelung G, Suredi B, Cheng P, Fisher J, Bux B, Miller M, Forcades M, Montes M, Diaz M, Gupta M

Background
Tuberculosis (TB) is a global health problem that affects millions of people every year. In Toronto and Barcelona, TB remains a significant public health concern. The purpose of this project was to facilitate the voices of individuals diagnosed with TB in Toronto and Barcelona through Photovoice.

Methods
The project was conducted in two phases. In the first phase, individuals diagnosed with TB in Toronto and Barcelona were recruited to participate in the project. In the second phase, the participants were provided with cameras and encouraged to take photographs that represented their experiences with TB.

Results
The project resulted in a collection of photographs that represented the experiences of individuals diagnosed with TB in Toronto and Barcelona. The photographs were used to create a monographic book and were also displayed in a hall exhibition.

Conclusions/Key Recommendations
The project demonstrated the value of Photovoice in facilitating the voices of individuals diagnosed with TB. The photographs provided a unique perspective on the lived experience of TB and highlighted the need for improved TB prevention and treatment programs.

Acknowledgements
The project was supported by the Toronto Public Health and the Barcelona Public Health Agency.

Stigma
The project aimed to reduce the stigma associated with TB by providing a platform for individuals to share their experiences.

Coping Mechanisms
The project explored the coping mechanisms used by individuals diagnosed with TB to manage their condition.

New Beginnings
The project explored the hopes and dreams of individuals diagnosed with TB for the future.

Challenges
The project identified the challenges faced by individuals diagnosed with TB in Toronto and Barcelona.

Participation
The project encouraged participation from individuals diagnosed with TB in Toronto and Barcelona.

La visión de los pacientes sobre la tuberculosis a partir de sus fotografías
Patient Perspectives of the Lived Experience of Tuberculosis Through Photos

A group of individuals diagnosed with TB are standing in front of a wall displaying their photographs. The wall is titled "La visión de los pacientes sobre la tuberculosis a partir de sus fotografías".

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MADRID 2017
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El proyecto Photovoices: dar voz a los pacientes con tuberculosis y que no tienen voz

Gerevive Amelung (1), Nuria Forcades (1), Maria Montes (2), Joan A. Diaz (2,3), Joan-Pau Millet (1, 2, 3).

1. Unidad Clínica de Tratamiento Directamente Observado (Servicio Clínico), Barcelona. 2. Servicio de Epidemiología, Agencia de Salut Pública de Barcelona. 3. Centre de Epidemiologia i Recerca sobre Malalties, Espana.

INTRODUCCIÓN
Photovoices es un método de investigación participativa que utiliza la fotografía como medio para dar voz y entender la experiencia del paciente al estar enfermo de tuberculosis (TB). Utilizado previamente en Toronto, las "nuevas fotografías" se han utilizado para apoyar la promoción y planificación de programas para comunidades marginadas y ha permitido a las personas convertirse en potenciales catalizadores para la acción y el cambio social. El objetivo del estudio fue proporcionar una oportunidad para que las personas con TB compartieran sus experiencias a través de fotos y de un texto realizado por ellos.

MATERIAL Y MÉTODOS
Se seleccionaron pacientes con TB mayores de edad, ingresados en Serveis Clínic, centro de referencia de TB en Cataluña, de abril a Agosto de 2016. Se escogió un perfil variado de pacientes en cuanto a edad, sexo, país de procedencia y factores de riesgo como indígenas, etnia o ser VIH. Se proporcionó una cámara digital y orientación sobre el proyecto subrayando la importancia del anonimato y del tema libre. Dos investigadores agruparon, clasificaron y analizaron las fotografías por temas, de forma independiente primero y consensuada después, según la vivencia de la enfermedad.

RESULTADOS
Participaron 16 pacientes (rango de edad 15-63 años), nacidos en diferentes países endémicos de TB. Se recogieron un total de 83 fotografías con un texto de apoyo. Las imágenes se clasificaron en 11 temas: desafíos, aislamiento, estigma, resiliencia, nuevo inicio, cosas que echo de menos, mecanismos de ayuda, pensamientos positivos, un parón en mi vida, lucha y estigma.

CONCLUSIONES
El proyecto ofrece una plataforma creativa y viable para que las personas diagnosticadas de TB expresen y compartan sus experiencias. La difusión de estas imágenes y textos en diferentes webs y varias plataformas, ayudará a aumentar la comprensión y la sensibilización sobre la TB. Photovoices podría ser una herramienta eficaz para ser utilizada en todos los programas de TB a escala mundial y ayudar a mejorar el apoyo, la atención y los servicios que se dan a los pacientes con TB.

Contacto:
Dr. Joan-Pau Millet jmillet@barcelona.cat o serveisclinics.com

EXPOSICIÓ Art i Salut
Tuberculosis Barcelona Photovoices:
"Donar veu als que no tenen veu"

Lloc
Sala d'actes, ASPB
Pl. Lesseps, planta 1r 1a
Barcelona

Dia:
Dijous 11 d'Octubre de 2018

Hora
9.45 a 11.00h

Art i Salut
Consorci Sanitari de Barcelona
Agència de Salut Pública

- Effective tool for storytelling
- Created community opportunities
- Evaluation Responses
- Photos will be used in multiple platforms
- TB Photovoice in Barcelona, Spain
- Increased awareness

“We are not superheroes. We need a helping hand when we are sick.”

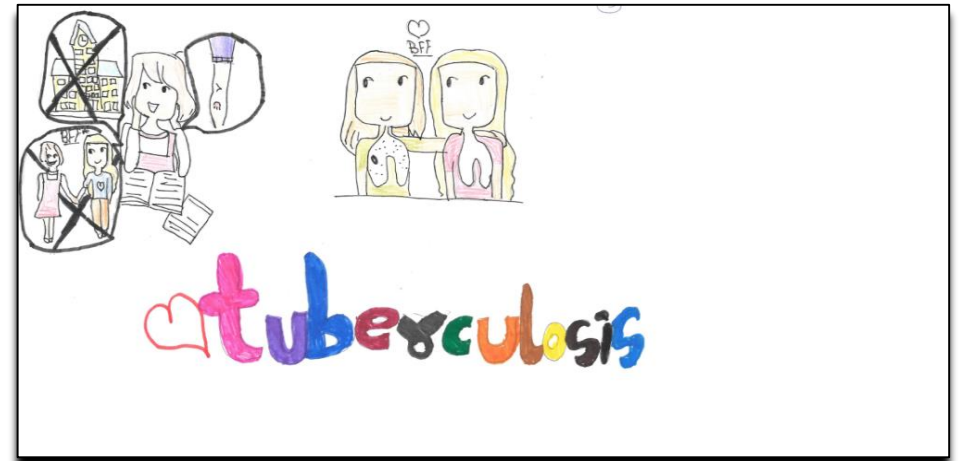
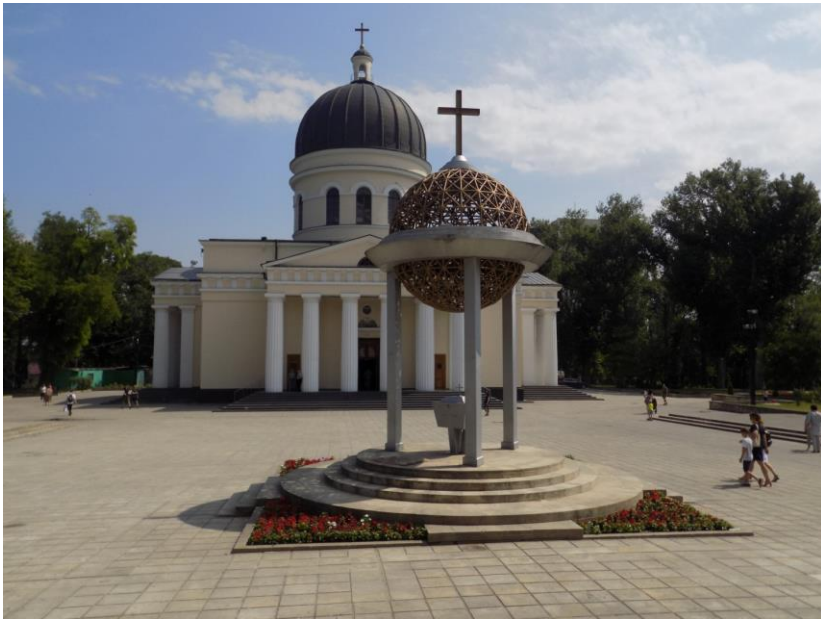


INNOVA4TB: Photovoice Moldova

- INNOVA4TB: Photovoice Moldova. Institutul de Ftiziopneumologie"Chiril Draganiuc". Chisinau: 10 participants july/19 (70 pictures). Under analysis

Pediatric Photovoice: Barcelona

- Multisite project among pediàtric TB patients: Under enrolment (11 children): pictures or photos and a survey for a qualitative analysis and psychologist.



*Faith is the treatment that heals ephemerity,
having a beneficial and meaningful effect.
Anastasia*

Thank you



Si tienes TB, necesitas superarla (nadando, haciendo el tratamiento) y puedes llegar al final.

Having TB you have to keep going (keep swimming, get through treatment) and you can arrive at the end.

Anónimo