

Photovoice for patients with myelodysplastic syndrome - to understand the patient's story

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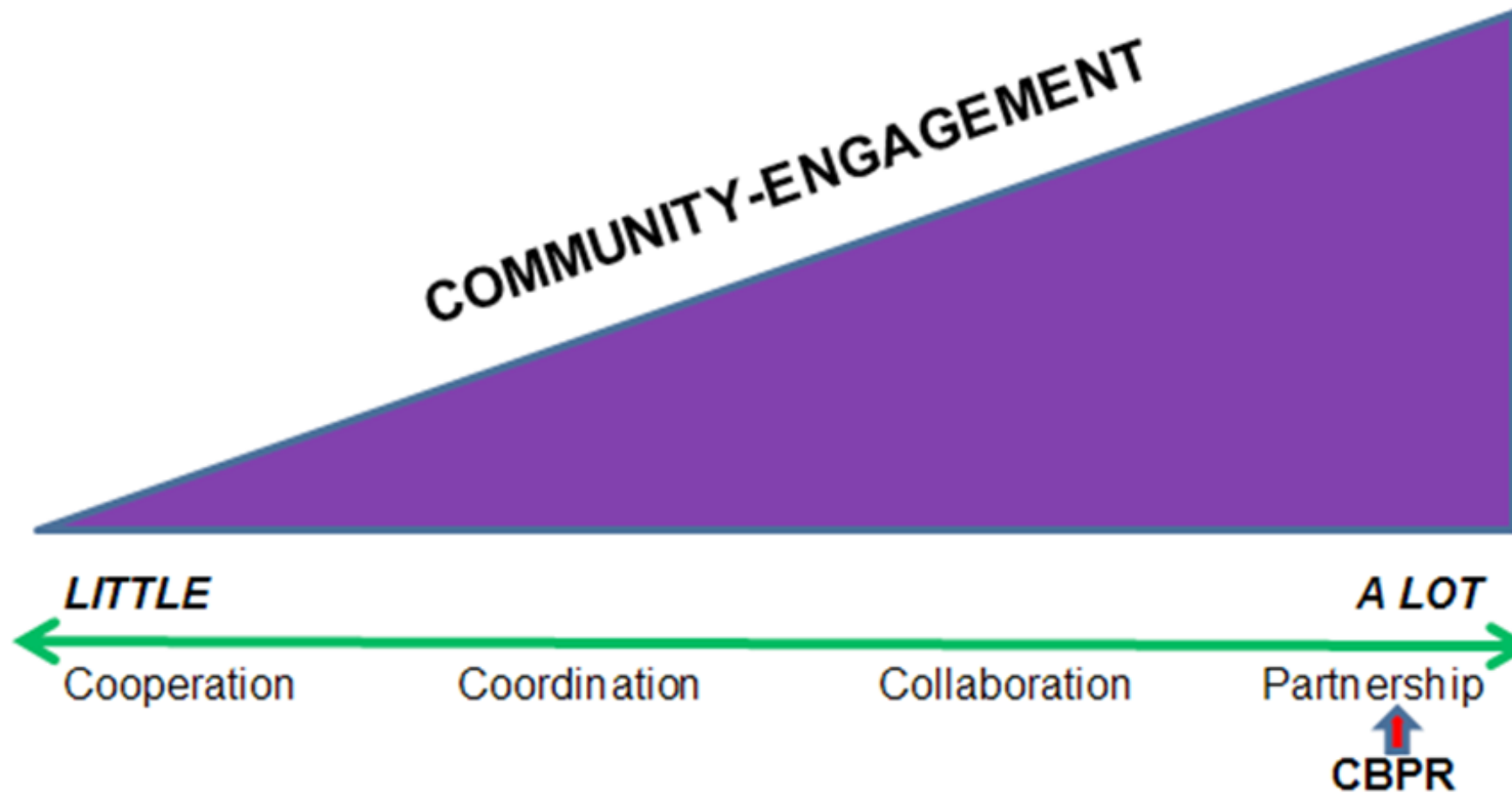
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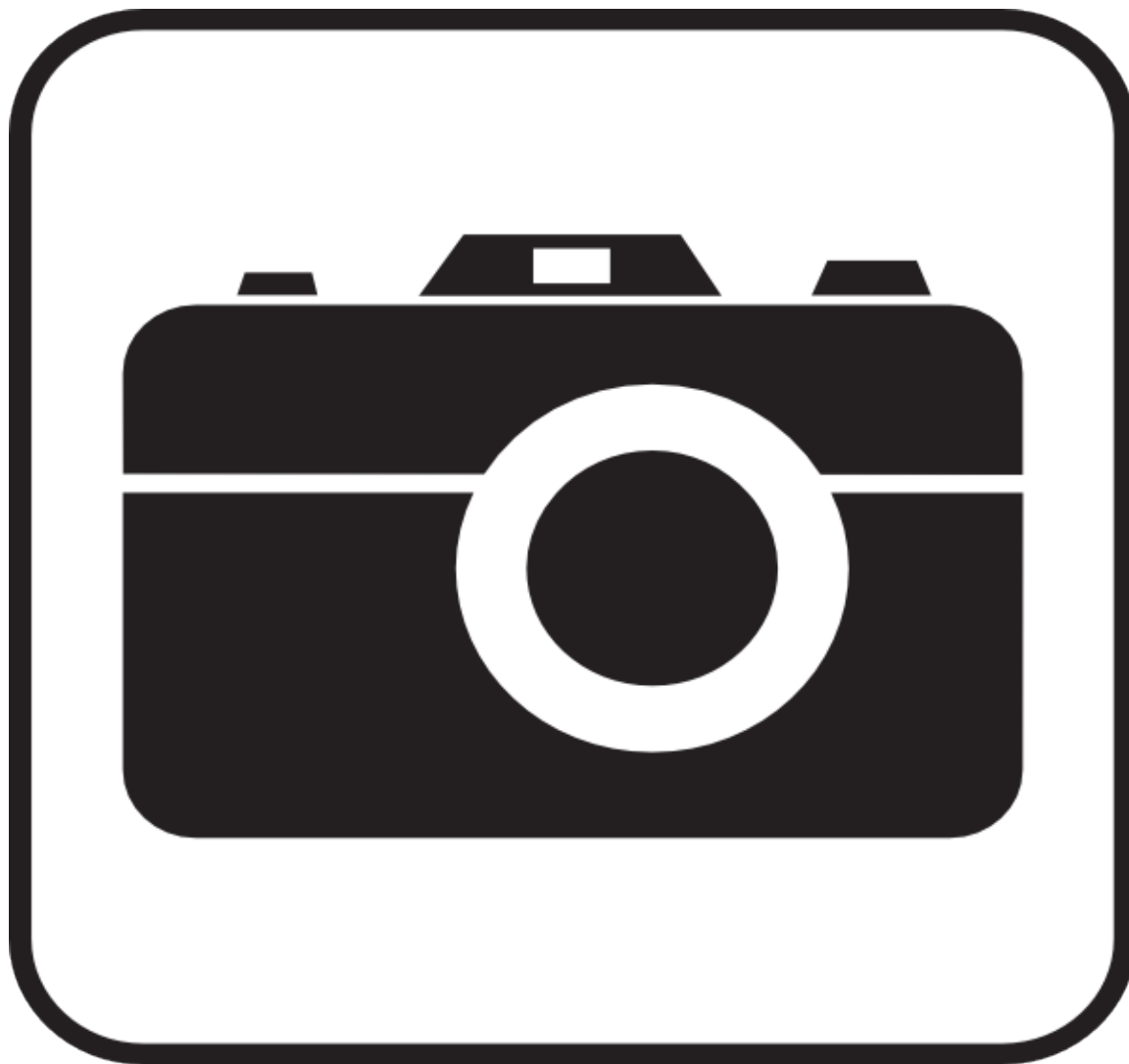
Participatory action research (PAR)

- Based on joint participation and action- act *together* for a better outcome
- Research *with*, not on
- Scientific methods are *adapted* to the specific/current problem
- Knowledge is gained *commonly* and should be useful in practice

Brydon-Miller and Maguire 2008; Baum et.al. 2006



Vaughn, 2015



SHOWED model

What do you **See** here?

What is really **Happening** here?

How does this relate to **Our** lives?

Why does this situation, concern, or strength exist?

Empowerment- how can this story strengthen the patient?

What can we **Do** to improve the situation, or to enhance these strengths?

Brydon-Miller, 2008; Koch T, 2006; Wang and Burris, 1997

Our research group

- Doctor and nurses with patient awareness
- Quality manager from Cancer Centre West
- Supervisor from CHI
- Patients with MDS



Patient selection

Inclusion

- >18 years,
- Current active treatment for MDS
- MDS diagnosis >3 months
- ECOG Status 0-2 at diagnosis
- Preserved cognitive function

Exclusion

- Patients with reduced cognitive function
- Unable to take pictures/handle a smartphone or a camera
- ECOG Status >2 at diagnosis

Research questions

1. To increase knowledge for and to gain better understanding for the daily life for patients with a blood disease to better support the patients own force to cope with the disease.
2. By the shared patients stories, start improvement work at the out patient clinic to improve the support for other patients with similar blood diseases

Implementation

- 18 patients were identified from our out-patient clinic and were asked,
 - 6 ECOG >2
 - 2 excluded
 - 10 eligible
 - 6 patients declined
 - 4 patients accepted

- 2 men, 2 women
 - Age 65-79 year
 - All with university education (!)

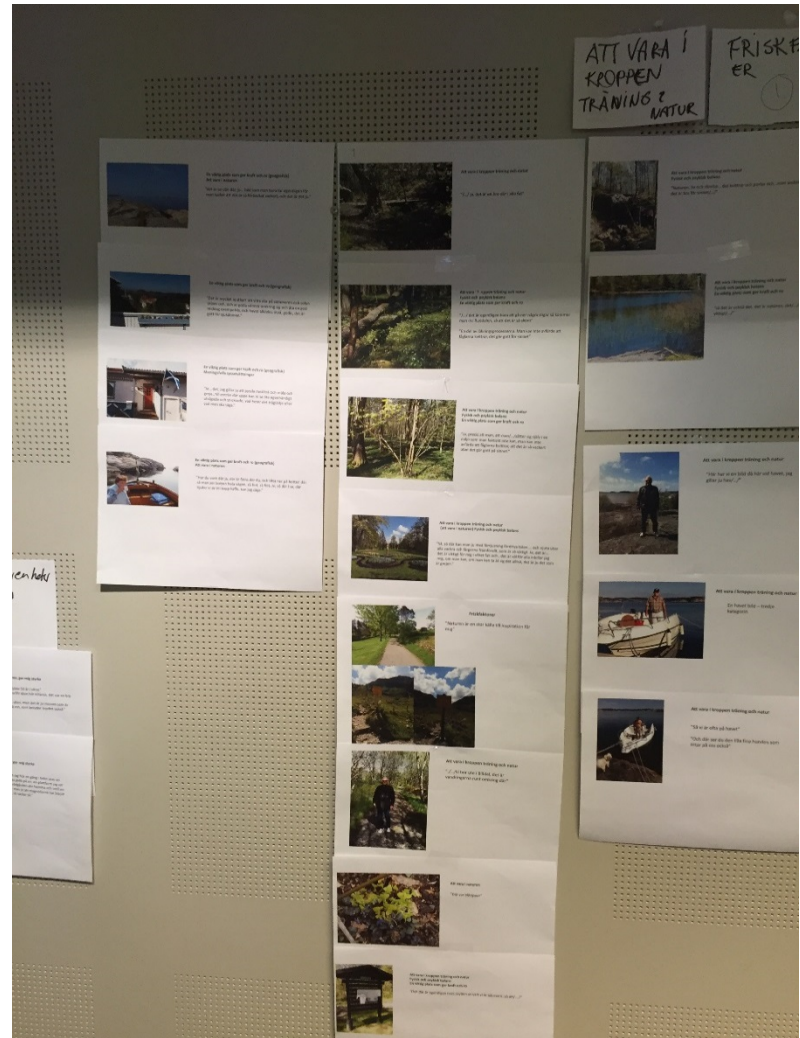
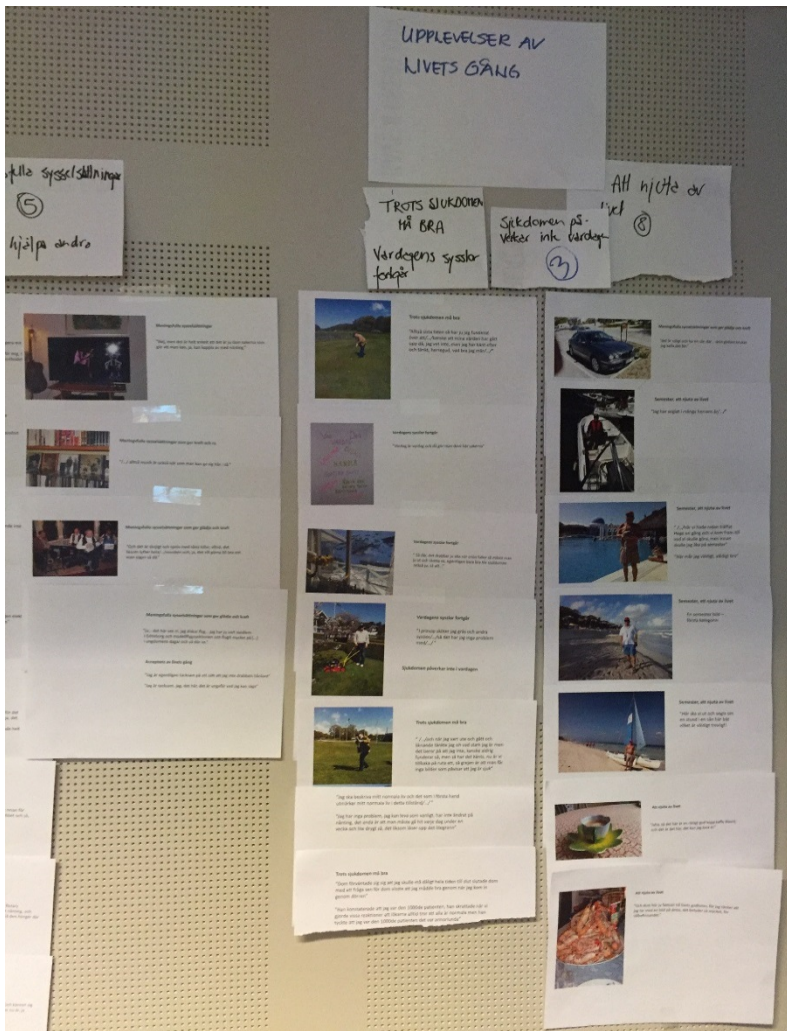
Implementation

- Start meeting with the patients
- "Describe with a picture (or a text) how it is living with MDS"
 - >Maximum 30 pictures
- Start March 2015

Implementation

- Two weeks of the patients taking pictures
- Individual meeting with the patients
- Transliteration
- Dialogue meeting
- Thematizing
- Categorizing

Categorizing of the pictures



PHOTOVOICE FOR PATIENTS WITH MYELODYSPLASTIC SYNDROME
- TO UNDERSTAND THE PATIENT'S STORY

Six categories

1. Being an individual person – more than a diagnosis
2. Experiences of living with the disease
3. Experiences of meeting the health care system
4. Strategies for coping with the disease
5. Strategies for well being despite the disease
6. Living here and now, accepting the disease

What did the pictures tell us?



1. Being an individual person – more than a diagnosis

Social networks, the family gives comfort and hope

She is thus my life companion and escort through this disease, and nags at me when needed and helps me in all situations and I cannot have it any better, I am extremely happy and so it should be



1. Being an individual person – more than a diagnosis

Social networks, a free zone

*We call us the oyster gang/..they call
almost every day and ask how I am, not
now then but when I have been ill and
admitted and so they have come to visit
me*



2. Experiences of living with the disease

The disease limits life, physically and mentally

/../My living room window. But life goes on out there anyway, yes/../

It is a sign of loneliness which have been forced upon you. A feeling of desolation.



2. Experiences of living with the disease

The disease induces feelings

Or one wonder a bit how this person is feeling...so it is actually this sadness that one can sometimes feel, that I thought was...how should you say, portrayed in a way



2. Experiences of living with the disease

The disease creates claim and musts that affects daily life

... but this is a new part of my life...here I am often

3. Experiences of meeting the health care system

The health care service important to continue the life journey that has stopped

So they said this, you are too healthy for any treatment but at the same time you can not go to the movies and you can not do this because it is a huge risk factor and I said: one can not live like that!

3. Experiences of meeting the health care system

The health care service can give hope

After dialogue with the treating physician and meeting with the transplant team a way opened up that me and my family could embrace. In reality hard decisions is postponed, an insight that it is not such a rush and that my treatment team continues to control my condition. I feel secure knowing this and the knowledge that there is a cure any way, I like to think so

4. Strategies for coping with the disease

Having meaningful occupation

*Books means a great deal,
otherwise I would climb the
walls*





4. Strategies for coping with the disease

Accepting the must, demands to manage the disease

I thought, we can't have it like this, so I asked my wife if she had an old stay up stocking, which she had, and then I could fixate the bandages. It worked very well I can say



5. Strategies for well being despite the disease

An important place that gives strength and peace

It's really only to walk down some paths and then you are in Ruddalen, it's so nice/..a part of the healing process. You can't dismiss that the birds are singing, it makes good for the mind



6. Living here and now, accepting the disease

Enjoying life

And these are a part of the good things in life, so I thought, I will bring a picture of this, it means so much, for the well being



6. Living here and now, accepting the disease

Everyday chores continues

*Every day is living and
then you do these things*

Lessons learnt

- Is this new research?
- Homogeneous and small group of patients?
- Difficult method for the patients?
- Care for the material
- Learning by doing

Take home messages

- See the person behind the disease
- Try to understand the patient perspective/Choice of language
- Increased understanding for the patients experience living with MDS
- Photovoice is empowering for the patients
- Despite the disease life is worth living

Acknowledgements

➤ Our patients that provided the material

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