



European Cancer
Patient Coalition

Social Disparities in Europe

Patients: key challenges and actions - recommendations

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Workshop on Social Disparities in Cancer -ECPC Annual Congress



Challenges Patients Face

Related to their cancer pathway

- Screening - Diagnosis time
- Treatment time
- Following end of treatment
- During Survivorship

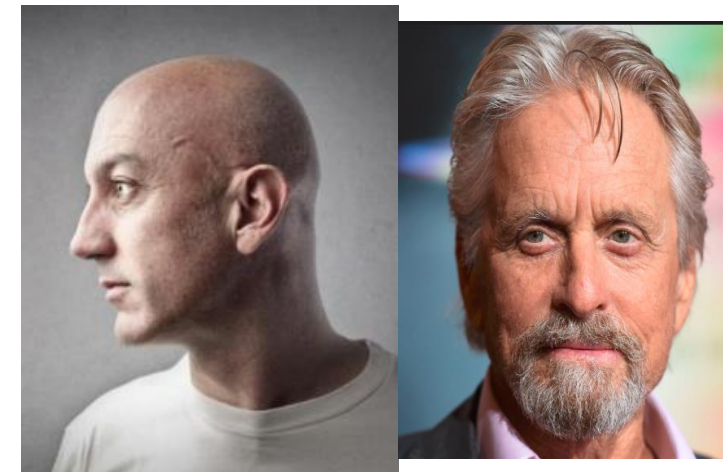


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Challenges Patients Face

In relation to patients' socio-economic status

- Income
- Place of residence
- Health Literacy
- Digital Literacy
- Communication skills
- Care network





Challenges Patients Face

Screening – Diagnosis Time

- Expert Physician – Cancer Center search
- Making sense of diagnosis
- Sharing news to family, children, friends

During treatment time

- Ability to discuss treatment options
- Manage anxiety, fear
- Coping with fatigue, distress, adverse events
- Caring for self and the family
- Seeking information about social insurance benefits
- Employment and income issues

End of Treatment – Survivorship

- Follow-up care plan
- Coping with long term effects of treatments
- Coping with relations within the family
- Financial toxicity of cancer care
- Return to employment
- Temporary or permanent pension due to disability from disease
- Adopting secondary cancer prevention measures



Challenges Patients Face

Socio-economic aspects

- **Income**

- Loss/reduction of income
- Inability to cover care/living costs

- **Place of residence**

- Access to cancer centers limited by distance
- Remote/rural areas

- **Health Literacy**

- Important for following treatment instructions
- Key for efficient patient – doctor communication

Digital Literacy

- Important for communication
- Facilitates access to information

Communication skills

- Facilitate communication with care team, family and friend
- Allows patient to better and more clearly express his needs

Care network

- Care network of family members, friends, relatives, colleagues to help with house chores & children

“Patients perform better when we are informed better”

*epatientDave de Bronkart
ECPC Congress June 2016*



"We perform better when we're informed better."
European Cancer Patients Coalition AGM June 2016

Amazing changes in who has information are giving patients power



Bringing together e-patients and health care professionals

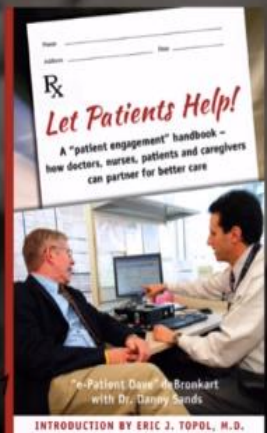
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INTRODUCTION BY ERIC J. TOPOL, M.D.



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Patient & families information & support needs

When you have cancer, current and accurate information can make the difference
Cancer patients

Cancer patients need to make **evidenced healthcare decisions in very short time**

- Understand their disease
- Contact the right expert
- Connect and communicate with other patients
- Understand benefits of participation in clinical trial
- Make decisions about their treatment
- Get informed about drugs interactions, about the importance of adherence to their treatment
- Adapt their lifestyle to the needs of their treatment and care

How easy is access to information cancer patients need?

Patients and patients' representatives need multi-level access to information

- Information is a basic right of patients to make medical decisions together with their physician
- Levels of information, health literacy and language literacy are different for each patient - it is not possible to get the same information for everyone
- Patients need support to understand what their doctor tells them and to prioritize the questions they will ask their doctor



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Centrally available, accredited information portals: do they cover patient information needs?

- Cancer is not one disease: it has too many variations
- Centrally-available, accredited information portals unable to cover the cost of so many different cancers
- Important role of patient organizations
- The involvement of civil society, although covering a large part of patient care, is not recognized





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Role of cancer patient organizations in alleviating the challenges of cancer patients

Patient organizations offer:

- Peer support of patients and families
- Patient education
- Practical information
- Cancer advocacy for necessary policies
- Collaboration in research
- Often the only information resource for patients & families





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Thank you for your attention

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