

Maggie's Centres – providing cancer
support around the kitchen table
Dr. Alison Themessl-Huber



Europe's Beating Cancer Plan

In **2020**

- ◆ **2.7 million** people in the EU were diagnosed with cancer
- ◆ **1.3 million** people died as a result of cancer

How many people were affected by cancer?
mother, father, sister, brother, friend....

By 2035 cancer could be the leading cause of death in the EU!

(Source:https://ec.europa.eu/info/strategy/priorities-2019-2024/promoting-our-european-way-life/european-health-union/cancer-plan-europe_en)

The good news

- ◆ More people are surviving cancer!
 - Prevention
 - Early detection
 - Effective treatments

- ◆ In Europe
 - Estimated to be more than 12 million cancer survivors

Cancer survivorship- one definition

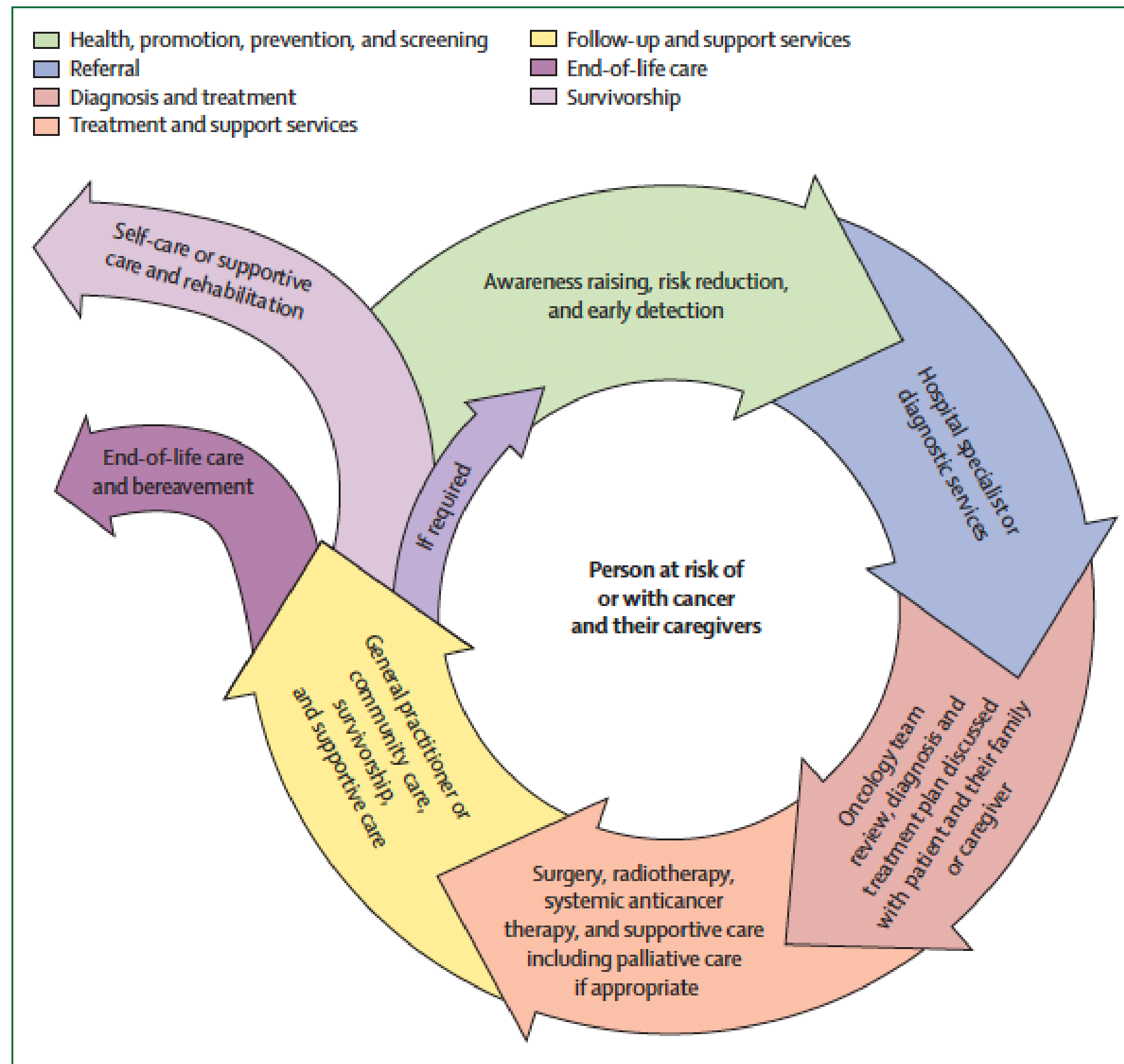
*“ In cancer, **survivorship** focuses on the **health and well-being** of a person with cancer **from the time of diagnosis until the end of life.***

*This includes the **physical, mental, emotional, social, and financial** effects of cancer that **begin at diagnosis and continue through treatment and beyond.***

*The survivorship experience also includes issues related to **follow-up care** (including regular health and wellness check-ups), **late effects of treatment, cancer recurrence, second cancers, and quality of life.***

Family members, friends, and caregivers are also considered part of the survivorship experience.”

Cancer Care continuum and nursing



Prevention
Early Detection
Treatment
End-of-life
Survivorship

Figure: Cancer care continuum

Source: Young et al. *Lancet Oncol* 2020; 21: e555–63

Survivorship- *"One size is not likely to fit all"* (Chan et al. 2021)

Healthcare delivery and follow-up

Management of comorbidities

Physical activity and exercise

Healthy lifestyle changes

Disparity and social determinants of health

Employment

Management of symptoms/toxicity/late effects

Psychosocial care

Health communication

Management of comorbidities

- ◆ In the UK
 - 70% of cancer survivors are also managing other long-term conditions (e.g. diabetes or cardiovascular problems). (MacMillan (2019))
- ◆ In Europe 23.5% of the working population have a chronic disease (Scarattie et al, 2018)
 - 2 out of 3 people at retirement age have at least two chronic conditions (RIVM, 2012)

People affected by cancer-what do they want?

What questions could people diagnosed with cancer have?

How am I going to tell my friends, family, children?

How will my life change?

Will I be able to work and pay the bills?

Should I have asked more questions? How do I find out more?

How do I get back to normal now that I've finished treatment?

What can I do to reduce the risk of cancer returning?

"I was just sort of left in this really helpless and bewildered kind of state, but **it felt like nobody cared about, really.**"*

"They don't want you to talk about it because it's just so upsetting so you're in a very difficult position because **you're not allowed to talk about it or refer to it.**"*

*source: <https://healthtalk.org/colorectal-cancer/breaking-the-news>

And families and friends...

What do I say to my friend who has cancer?

How do I tell my boss I need time away from work?

What can I do to help my children feel better?

Will my husband die?

“Initially when the word ‘**cancer**’ was mentioned- terrible thing, that’s **death to me**”.*

“Living hell- **no support** whatsoever from anybody”.*

“...would I be there when she needed me?...**would I be strong enough...?**”*

*Source: Harrow, A. Thesis ‘Betwixt and Between’: The Male Partner’s Experience of Breast Cancer

Breast cancer- the patient journey



Diagnosis



lack of tailored **information**, inconsistent roles in supporting wives/partners- could lead to **fear and anxiety** and inability to provide ongoing support

misinterpretation and misunderstanding could lead to **anxiety and fear**

ARTICLE IN PRESS

European Journal of Oncology Nursing (2008) 12, 111-114

Available at www.sciencedirect.com





journal homepage: www.elsevier.com/locate/ejon

Ambiguity and uncertainty: The ongoing concerns of male partners of women treated for breast cancer

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KEYWORDS

Male partner;
Ambiguity;
Uncertainty;
Experience

Summary

As the prevalence of breast cancer increases, survival improves and short stay or outpatient care become the norm, greater numbers of men will be involved in providing care and support for their partners at home. This qualitative study explored the experiences of 26 male partners of women who had completed treatment for breast cancer. A questionnaire was developed in order to collect background information and to provide a pool for further qualitative sampling. One hundred and five questionnaires were distributed, 79 returned and 26 one-to-one interviews were conducted. While negotiating

ELSEVIER

Patient Education and Counseling
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“Seeing is believing, and believing is seeing”: An exploration of the meaning and impact of women's mental images of their breast cancer and their potential origins

Alison Harrow^a, Mary Wells^a, Gerry Humphris^b, Cara Taylor^c, Brian Williams^d & 

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https://doi.org/10.1016/j.pec.2008.07.014

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Abstract

Objective

To explore the nature, meaning and perceived origin of women's mental images of their breast cancer.

Methods

Fifteen women, who had completed treatment for primary breast cancer, participated in this qualitative study. Data were analysed using the “network” method.



Treatment

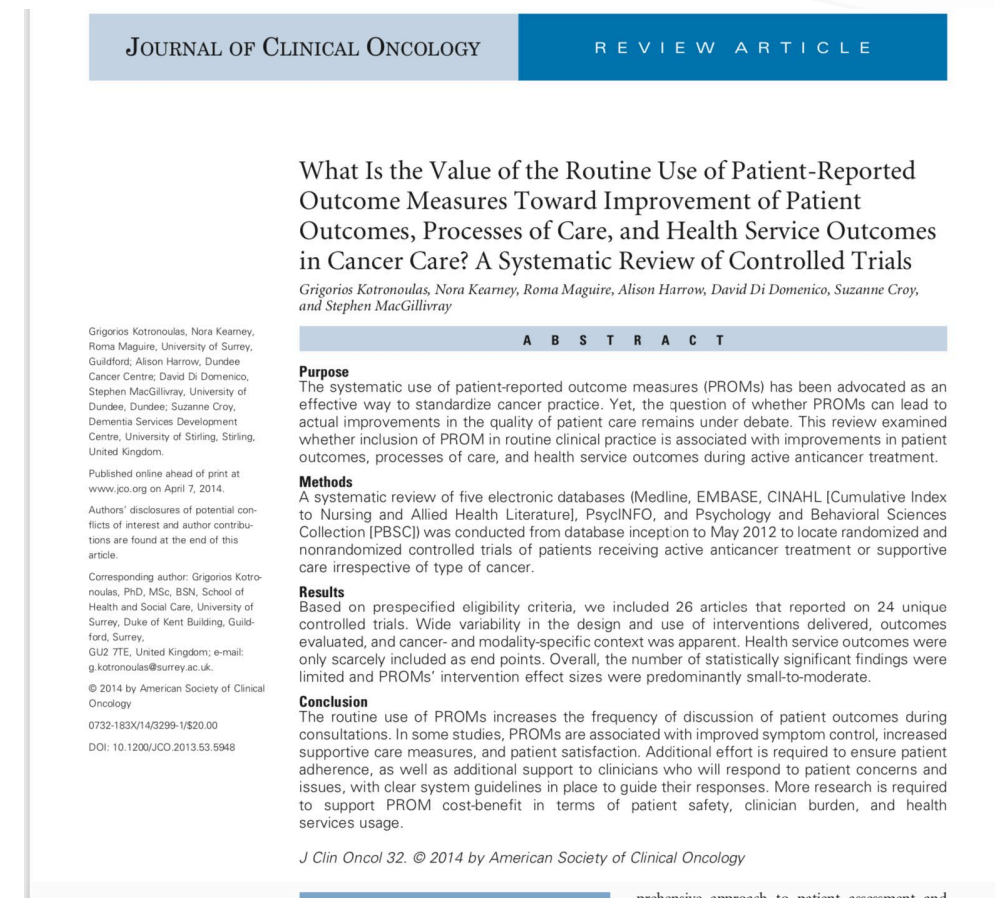
Quantitative research

RCT- Nurse-led supported early discharge

Reduced hospital stay but potential for reduced **support** and opportunities to ask questions (women with cancer and their carers), need for community-based care (cost)

Systematic Review

Use of Patient-Reported Outcome Measures increases frequency of **discussions** with health professionals about issues **important to patients**



Follow-up Care

Adherence to medication

There is a clear need to

communicate

consistently and

effectively about

endocrine therapy and its effects, and

to offer ongoing **support**

and advice in hospital

and community settings.

Open Access

Research

BMJ Open A hard pill to swallow: a qualitative study of women's experiences of adjuvant endocrine therapy for breast cancer

Alison Harrow,¹ Ruth Dryden,² Colin McCowan,³ Andrew Radley,⁴ Mark Parsons,⁵ Alastair M Thompson,⁶ Mary Wells⁷

To cite: Harrow A, Dryden R, McCowan C, *et al.* A hard pill to swallow: a qualitative study of women's experiences of adjuvant endocrine therapy for breast cancer. *BMJ Open* 2014;**4**:e005285. doi:10.1136/bmjopen-2014-005285

► Prepublication history and additional material is available. To view please visit the journal (<http://dx.doi.org/10.1136/bmjopen-2014-005285>).

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ABSTRACT

Objective: To explore women's experiences of taking adjuvant endocrine therapy as a treatment for breast cancer and how their beliefs about the purpose of the medication, side effects experienced and interactions with health professionals might influence adherence.

Design: Qualitative study using semistructured, one-to-one interviews.

Setting: 2 hospitals from a single health board in Scotland.

Participants: 30 women who had been prescribed tamoxifen or aromatase inhibitors (anastrozole or letrozole) and had been taking this medication for 1–5 years.

Results: Women clearly wished to take their adjuvant endocrine therapy medication as prescribed, believing that it offered them protection against breast cancer recurrence. However, some women missed tablets and did not recognise that this could reduce the efficacy of the treatment. Women did not perceive that healthcare professionals were routinely or systematically monitoring their adherence. Side effects were common and impacted greatly on the women's quality of life but did not always cause women to stop taking their medication, or to seek advice about reducing the side effects they experienced. Few were offered the opportunity to discuss the impact of side effects or the potential options available.

Conclusions: Although most women in this study took adjuvant endocrine therapy as prescribed, many endured a range of side effects, often without seeking help.

Strengths and limitations of this study

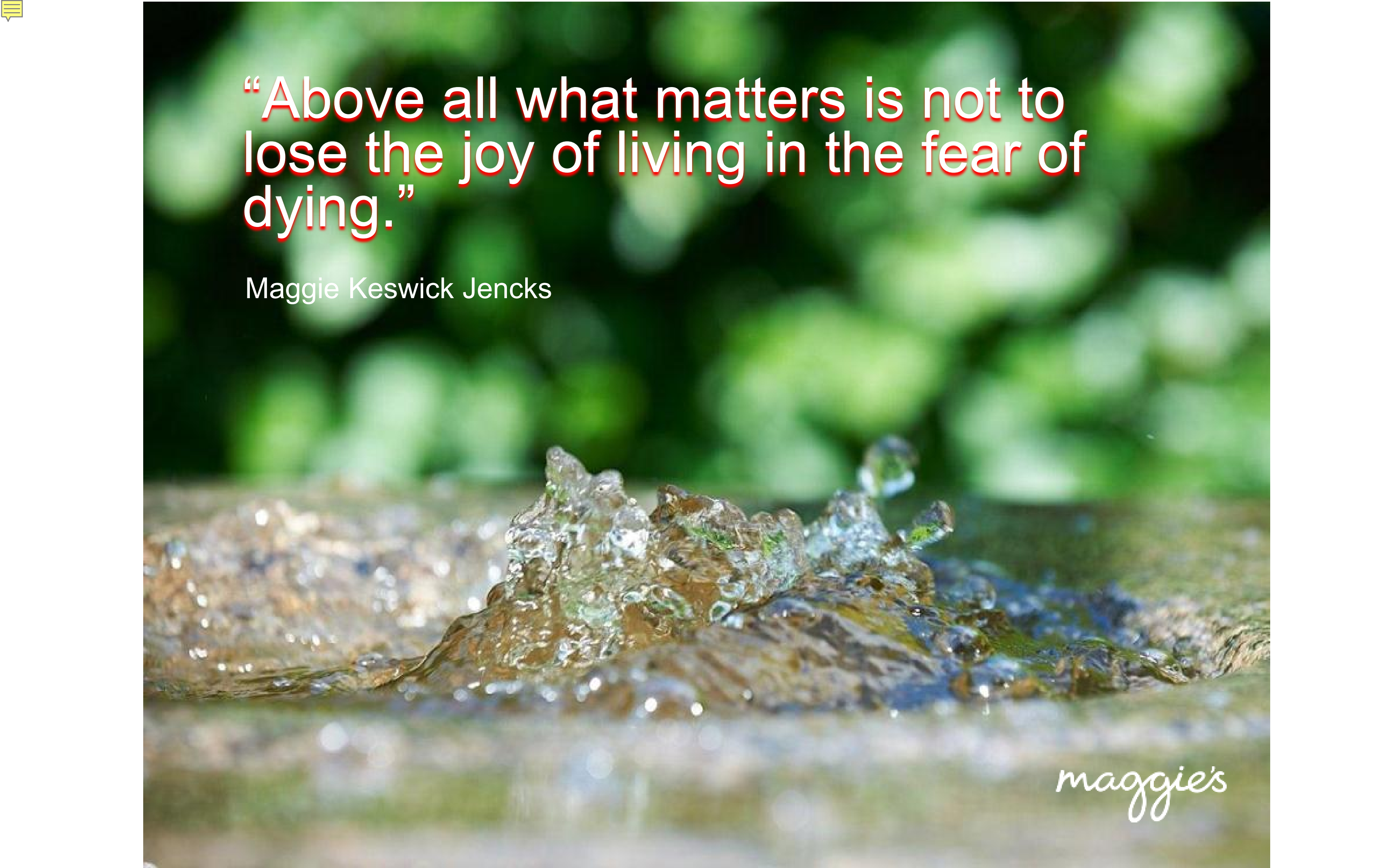
- This is one of the few studies which have asked women to talk about their experiences of taking adjuvant endocrine therapy for breast cancer.
- We found that women seek to be adherent but some will miss tablets without realising the potential consequences.
- The impact of severe side effects does not necessarily affect adherence, as women's belief that taking the medication reduces their risk of recurrence outweighs these negative effects.
- Not all women who experience side effects will seek advice and support. Opportunities for monitoring adherence to and managing symptoms of adjuvant endocrine therapy are underutilised.
- Women with low adherence and those who were premenopausal were under-represented in this study.

or, for postmenopausal women, aromatase inhibitors (eg, anastrozole or letrozole).^{2 3} Tamoxifen is a selective oestrogen receptor modulator, whereas aromatase inhibitors (AIs) reduce oestrogen synthesis by blocking conversion of androgens into oestrogen. Clinical trials have shown that tamoxifen reduces the risk of disease recurrence by 11.8% and mortality by 9.2% over 5 years.

Centre Head Maggie's Cancer Centre, Fife, Scotland

Fife has a similar population to Vorarlberg- 370, 000
3 major towns and many rural areas
Each year more than 8000 people visited Maggie's
Fife for support





“Above all what matters is not to
lose the joy of living in the fear of
dying.”

Maggie Keswick Jencks

maggie's

A legacy



Programmes of support



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JUST COME IN

Who we are

Maggie's is a charity providing free cancer support and information in centres across the UK and online.

How we can help

Our Support Specialists, Psychologists and Benefits Advisors are here, if you or someone you care about has cancer.

Time to talk

Share experiences with others in a similar situation around the kitchen table in a centre, or in our online community.

The kitchen table

Cancer Support Specialists

Having time to listen, acting as advocates, working with clinical staff

Clinical and Counselling Psychologists

Available for people with cancer and their families



Maggie's Fife: Source Environmental Psychology



Maggies Centre in London. Source Independent.org

Art, music, writing therapists
Relaxation, yoga, Tai Chi instructors
Nutritionists

At time of diagnosis



After treatment



When someone dies





International Centres

Maggie's Hong Kong

Maggie's Tokyo

Kálida Barcelona

Planned: Maggie's Oslo, Norway

Maggie's Groningen, The Netherlands



***"Maggie's is like an oasis.
It gives you the tools to take your
future forward, to take control of your life."***

Maggie's Vorarlberg?



LANDESKRANKENHAUS

← Parkgarage

Notfallaufnahme →

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