

“I’m So Glad I Met You”: Designing Dynamic Collaborative Support for Young Adult Cancer Survivors

Jordan Eschler
Wanda Pratt

YA Cancer and Information Needs

The Interview Study

Findings Related to YA Needs

Implications for Dynamic Support

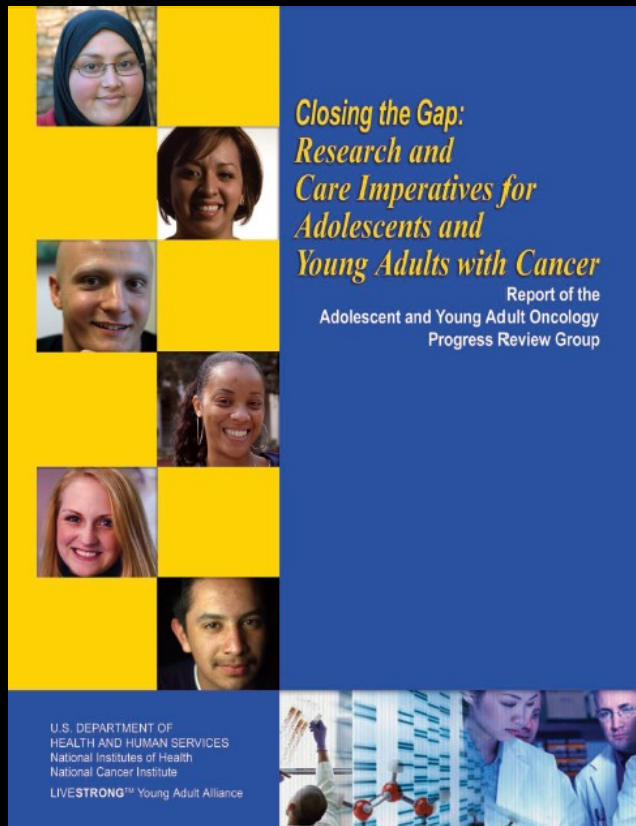
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Information needs for YA cancer



National Cancer Institute
AYA HOPE, 2006

YA cancer psychosocial needs*



Feeling isolated

YA cancer psychosocial needs*



Feeling isolated



Confronting a sense of mortality

YA cancer psychosocial needs*



Feeling isolated



Confronting a sense of mortality



Struggling with body image/identity

Dynamism of support: illness phases^{**}



^{**}Eschler et al., 2015 (ICWSM)
See also Ziebland et al., 2004; Hayes et al., 2008

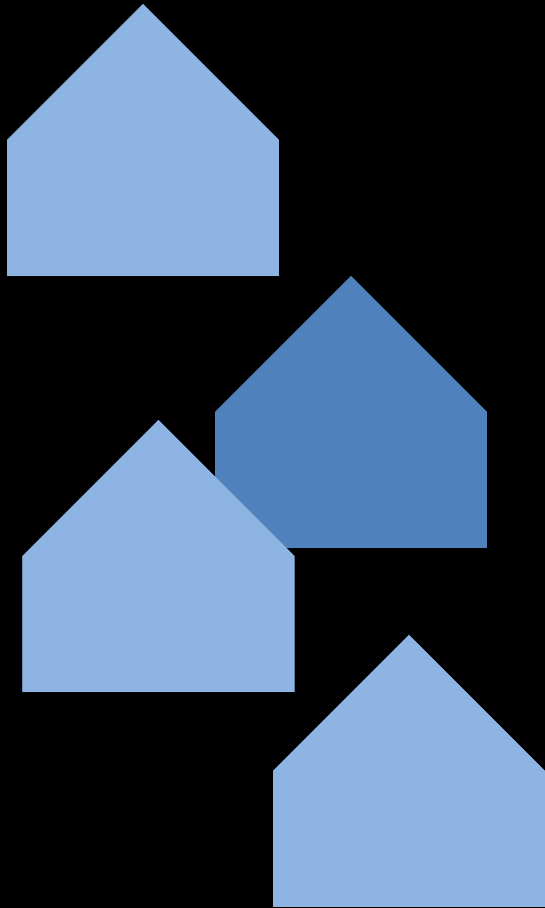
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Interview procedure



90 minutes

Semi-structured

In participants' homes

N=15 (4 male & 11 female)

Participants

Pseudonym (Gender, Age)	Diagnosis	Elapsed time from first diagnosis to interview date	General treatment course
Bob (Male, 35)	Hodgkin's Lymphoma, Stage 4	9 months	Chemotherapy
Marie (Female, 42)	Osteosarcoma*	30 years	Surgery, Chemotherapy
Leah (Female, 32)	Breast Cancer, Stage 4	1.5 years	Surgery, Chemotherapy, Radiation
Emily (Female, 35)	Hodgkin's Lymphoma, Stage 3	4 years	Chemotherapy
Jo (Female, 28)	Thyroid Cancer, Stage 1*	2 years	Surgery, radiated iodine
Kate (Female, 29)	Acute Lymphoblastic Lymphoma, Stage 4	4.5 years	Chemotherapy
Lucy (Female, 33)	Acute Lymphocytic Leukemia	4.5 years	Chemotherapy, Stem cell transplant
Peter (Male, 31)	Adenocarcinoma (head & neck)	9 months	Surgery, Chemotherapy, Radiation
Mark (Male, 32)	Brain tumor, Grade 2 or 3	1.5 years	Surgery, Chemotherapy, Radiation
Helen (Female, 31)	Cervical cancer, Stage 1B1	6 months	Surgery, Chemotherapy, Radiation
Michelle (Female, 37)	Cervical cancer, Stage 3	1.5 years	Surgery, Chemotherapy, Radiation
Diana (Female, 30)	Primary Central Nervous System Lymphoma*	2.5 years	Surgery, Chemotherapy, Stem Cell Transplant
Emma (Female, 28)	Thyroid Cancer, Stage 1	11 years	Surgery
J.C. (Female, 34)	Cutaneous T-Cell Lymphoma*	4.5 years	Chemotherapy, Stem cell transplant
Rico (Male, 23)	Acute Lymphocytic Leukemia	3.5 years	Chemotherapy, Radiation, Stem cell transplant

*Survivor has experienced recurrent or persistent cancer diagnosis

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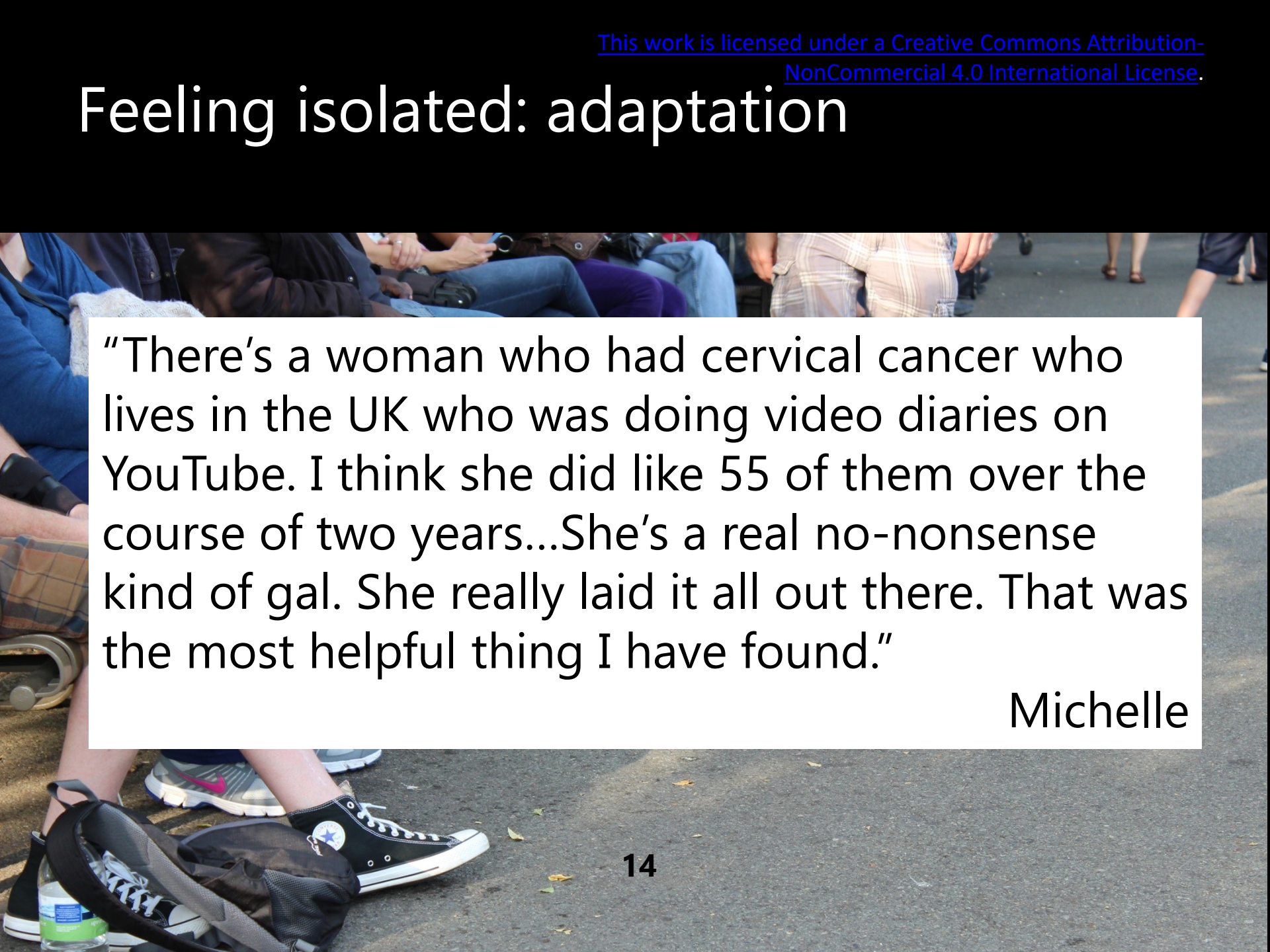
Findings Related to YA Needs

Implications for Dynamic Support

Feeling isolated



Feeling isolated: adaptation



"There's a woman who had cervical cancer who lives in the UK who was doing video diaries on YouTube. I think she did like 55 of them over the course of two years...She's a real no-nonsense kind of gal. She really laid it all out there. That was the most helpful thing I have found."

Michelle

Confronting mortality



Confronting mortality: adaptation

"As far as everybody else is concerned, I'm just going to the coast and we're taking [our son] to the aquarium and just – life is life like it regularly was."

Helen

Struggling with body image/identity

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Struggling with body image/identity: adaptation

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"I have a handicap placard [for my car]. Some days I am tired, my back is sore, and I'll use it. If I do use it, people are like [gives side-eye]. I had a lady – it was maybe a couple of months out – and I was just running in to get lunch real quick at Whole Foods and she kind of questioned me."

Leah

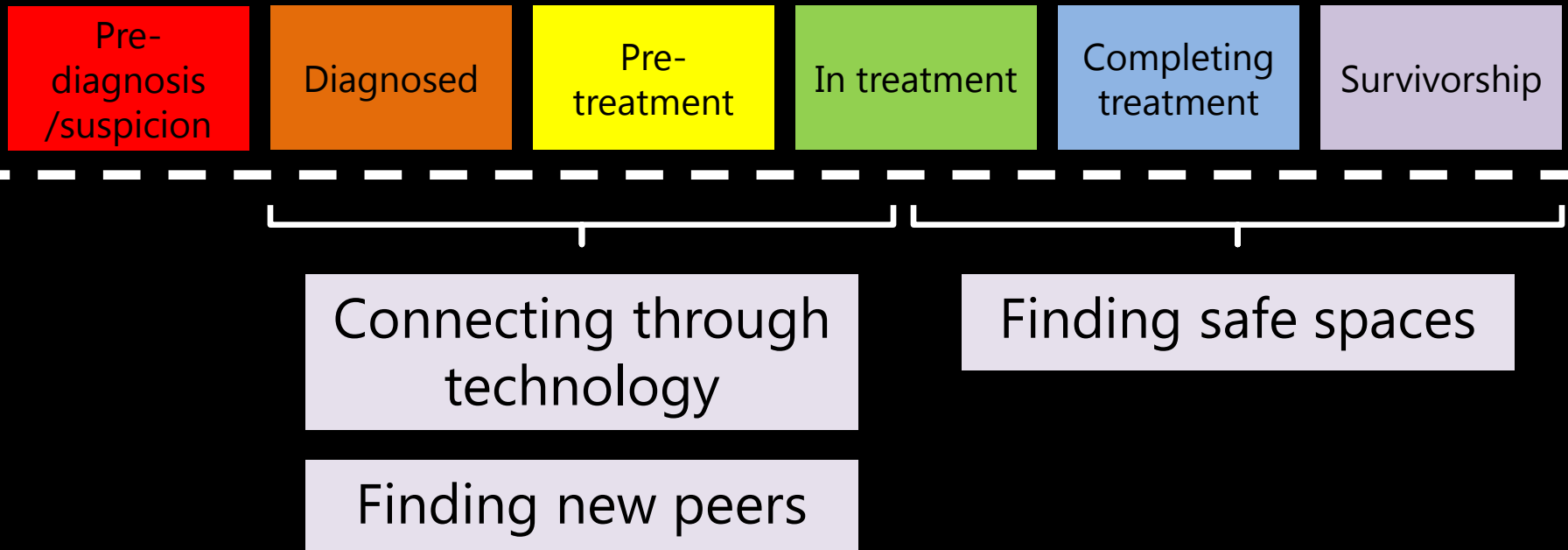
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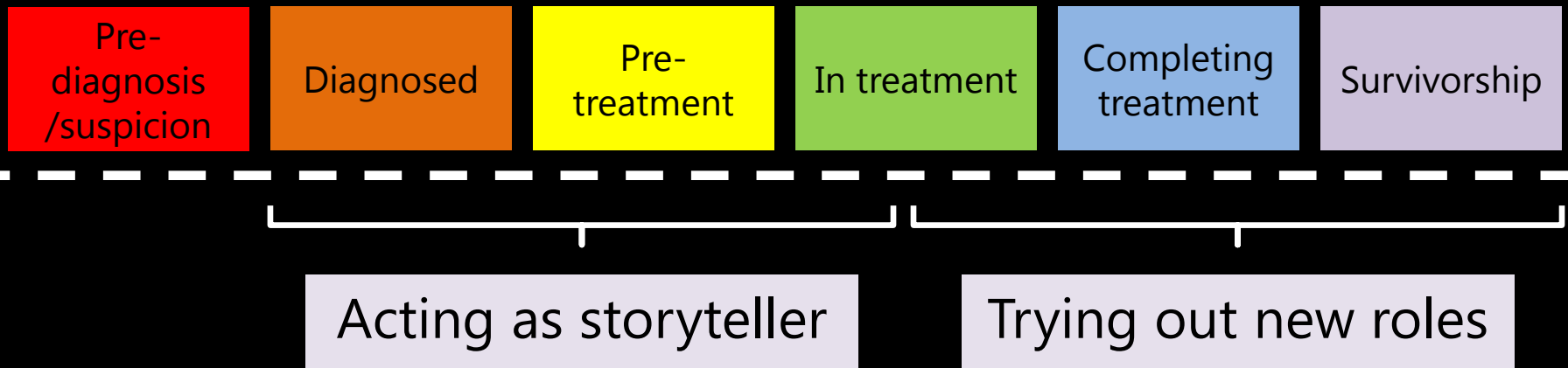
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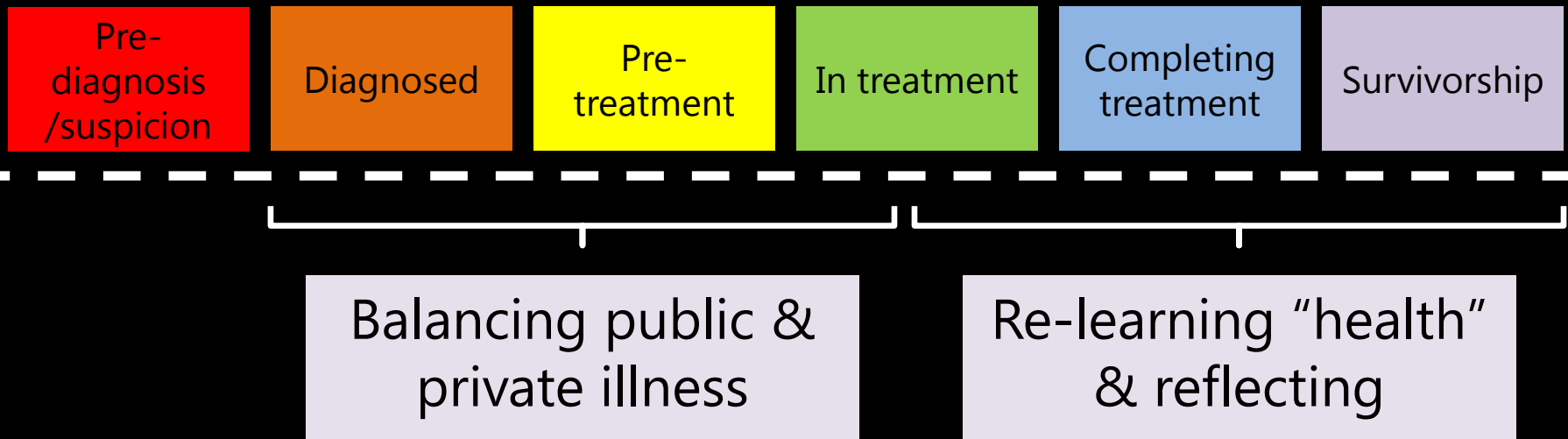
Feeling isolated: dynamic design = better peer matching



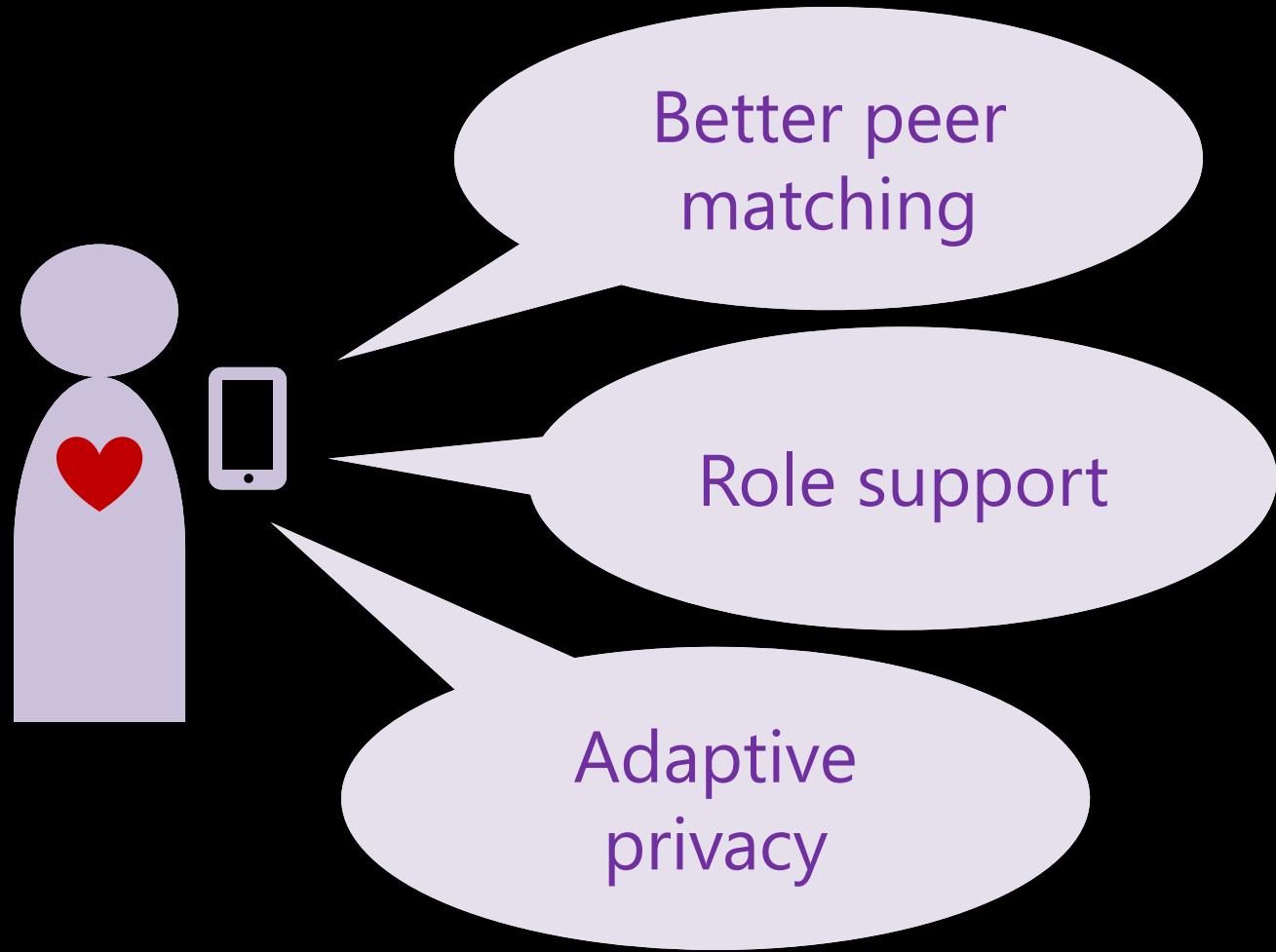
Confronting mortality: dynamic design = role support



Struggling with body image/identity: dynamic design = adaptive privacy



Conclusion: design opportunities



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Thank you also to my peer reviewers!

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Questions

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