Cancer of Unknown Primary

PATIENT PERSPECTIVE

the journey

Prior to diagnosis

Uncertainty.

Clear explanation in layman language.
Compassion.
Managing of expectations for the remainder of the journey.
Psychological support.
Availability and support of a case manager.

General practitioner

Patient shows up with a variety of symptoms, general anamnesis and diagnostic trajectory starts.
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Referrals take (too) long, patient is blaming himself as he feels he waited too long to make a GP appointment.

Continuously new and different emotions

During diagnosis

Disappointment, panic, sadness, anxiety, relieve.

Tailored & personal approach.
Friendly care environment.
Clear explanations.
Start of a dual care journey: diagnostics and palliative care.
Managing of expectations for the remainder of the journey.
CUP MDC.
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Hospitals

Metastases of an unknown primary, diagnostic work-up continues.

Information provision.
Too little time for a clear conversation.
Too many care professionals.
Limited specialist knowledge.
Unclear language.

Journey across different care professionals

Center of expertise

Diagnostics focused on detecting the primary tumor and/or treatable genetic mutations.

Too long diagnostic trajectory.
Too many different care professionals.

Lengthy diagnostic trajectory

After diagnosis

Uncertainty.

Clear communication.
Continuation of dual care journey.
Friendly care environment.
Need for physical, psychological and supportive care.

During treatment

In between hope and despair, uncertainty, frustration, anxiety.
Happy that a treatment has started.
Scared for check-ups.

Same as 'after diagnosis'.
Aftercare, farewell.

Targeted treatment

Treatment has the objective to slow disease progression and reduce symptoms.

2 types, according to:
- clinical guideline of detected primary tumor.
- a treatable genetic mutation.

Palliative treatment

Treatment has the objective to slow disease progression and reduce symptoms when no primary tumor has been detected. There is too little time, too limited quality of life. Diagnostic trajectory will be stopped.

Little involvement of GPs.
Missing aftercare journey for family members.

Feelings

Wishes

Hiatus

This project has been executed by the guidance of: Missie Tumor Onbekend By: cure concern connecting people

With support from: nfk Nederlandse Federatie van Kankerpatiënten organisaties; Patiëntenplatform zeldzame kankers; CZ

With financial support from: Roche; Bayer; Takeda

Cancer of Unknown Primary

CARE PROFESSIONAL PERSPECTIVE

the journey

General practitioner

Patient shows up with a variety of symptoms. General anamnesis and diagnostic trajectory starts.

logistics and referral system unclear.

Prior to diagnosis

Availability and support of a case manager.
Patients that learn to deal with uncertainty.
Clear information provision.
Regional care pathways and workflows.
Tight and collaborative care teams.
Maximizing patient expectations.

Lengthy diagnostic trajectory

During diagnosis

Challenging patient cases.

A clear point of contact for the patient.
A head practitioner.
Shortened diagnostic trajectory.
Optimize information provision.
Supportive and human approach to patient and family members.
Conformity in language used.
Regional network creation.
Improve WGS and other diagnostics.
CUP MDC.

Support during diagnosis

Psycho-social patient support.
CUP PROMs & PREMs.
CUP nurses.

Data collection to support national care pathway.

Hospitals

Metastases of an unknown primary. Diagnostic work-up continues.

Who is the point of contact for the patient?
Unclarity about logistics and collaboration between hospitals.
No conformity in language used.

Different hospitals without a head practitioner

Center of expertise

Diagnostics focused on detecting the primary tumor and/or treatable genetic mutations.

Diagnostic trajectory remains time consuming.
Opinions and interest of different care professionals.

After diagnosis

Patients that can process disease journey.
Each patient gets a palliative consultation.
Care offering for family members.

Targeted treatment

Treatment has the objective to slow disease progression and reduce symptoms.

2 types, according to:
- clinical guideline of detected primary tumor.
- a treatable genetic mutation.

Palliative treatment

Treatment has the objective to slow disease progression and reduce symptoms when no primary tumor has been detected. There is too little time, too limited quality of life. Diagnostic trajectory will be stopped.

Case manager for patient.
Missing aftercare journey for family members.

Feelings

Wishes

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