



SUMMARY DOCUMENT

COMPASS Strand 2 Scientific Session

“Interventions for Psychological Distress”

29th January 2008

**Mary Kinross room ♦ Queen’s Medical Research Institute ♦ New RIE♦
Little France ♦ Edinburgh**

EDINBURGH:

Dr Laura Hodges
Dr Annet Kleiboer
Elspeth Currie
Prof Michael Sharpe

LEEDS:

Kate Hill
Dr Galina Velikova

KINGS:

Prof Alison Richardson

1. Background

This report details the proceedings of the second scientific research session of the COMPASS Collaborative.

The aim of the meeting was:

- ◆ To develop ideas for an intervention for psychological distress in patients with cancer.

The programme is presented below:

Time	Item		
11.30– 11.35	1	Introduction: Setting the scene	Michael Sharpe
11.35 - 11.40	2	What is psychological distress?	Annet Kleiboer
11.40 – 11.45	3	What is a psychological intervention?	Laura Hodges
11.45 – 11.50	4	What is current practice?	Kate Hill
11.50 – 12.00	5	Introduction to the Group Activity	Laura Hodges & Annet Kleiboer
12.00 – 13.00	6	Preparing your ‘pitches’	Small groups
13.00 – 14.00	LUNCH		
14.00 – 15.15	7	Group ‘pitches’ to the panel*	Small groups & panel
15.15 - 15.30	TEA AND COFFEE BREAK		
15.30 – 16.00	8	What have we learned? Pulling it all together.	Panel & large group discussion

The following people attended the Board meeting and the Scientific Session:

Management Board/Administrators

Michael Sharpe
Scott Murray
Dan Stark
Alison Richardson
Amanda Ramirez
Matthew Hotopf
Galina Velikova
Julia Brown
Aziz Sheikh
David Weller
Marie Fallon
Mike Bennett
Elspeth Currie
Richard Garry
Susie Edwards

The following people attended the Scientific Session only:

Wider Collaborative

Dr Gillian McHugh
Prof Gerry Humphris
Dr Caroline Burgess
Dr Gozde Ozakinci
Dr Morag Farquhar
Dr Leanne Fleming
Dr Liz Forbat
Dr Jane Walker

Research Teams

Mrs Kate Hill
Dr Annet Kleiboer
Dr Laura Hodges

Invited Guests

Prof Neil Aaronson
Dr Lucy Wall
Mr Peter Rainey
Prof Gordon Murray

2. Presentations: Setting the Scene

The session began with brief presentations from the COMPASS Research Fellows. The presentations aimed to raise important questions and set the scene for the afternoon's group activity.

Annet Kleiboer's presentation focused on the meaning of the concept of psychological distress in cancer. This term is broadly defined and poorly operationalized, both with respect to its key components and its severity. That's why it is hard to compare studies on psychological distress and it is difficult to develop interventions. The presentation was a call for a better understanding of the concept of psychological distress; to determine the range of the concept, to match instruments to concepts and relate interventions to targeted groups.

Laura Hodges raised the question, 'what is a psychological intervention?' This term is used frequently in the cancer literature, but there is little consistency about what a psychological intervention is and on what criteria this is based. Some researchers define this concept very broadly, whilst others limit their discussions to specific types of intervention, often with little or no justification. This inconsistency is problematic and a framework of psychological interventions would be helpful in establishing a common language and allow tailoring of interventions in a clear manner to specific symptoms, patient groups, and delivery settings.

Kate Hill's presentation concerned current practice for dealing with emotional distress in oncology settings. A scoping study is being carried out to inform a national survey on the current practice of oncologists and other health care professionals to detect and manage cancer patient's emotional distress.

(Powerpoint slides available on request)

3. Group Activity: The Dragons' Den

The purpose of the group activity was 'brainstorming with a difference'.

Participants were divided into small groups and asked to design an intervention to reduce psychological distress in patients with cancer. Their aim was to prepare and present a 5-minute pitch to a panel (Dragons' Den) for intellectual buy-in to their project.

The dragons' included an oncologist (Dr Lucy Wall), a service user representative (Mr Peter Rainey), a medical statistician (Prof Gordon Murray) and a health psychologist (Prof Neil Aaronson).

The pitch had to include details of:

- Who the intervention will be for?
- What the intervention will be like?
- Who will deliver the intervention and where?
- Your outcome?
- How you will evaluate the intervention?

The pitch itself was to be made by a team spokesperson, but all members of the team were to be involved in answering questions put to them by the dragons.

4. Group 'pitches'

GROUP 1: Web-based intervention for distress in adolescents

Group 1 presented a pitch for a proof of concept web-based intervention.

This would be aimed at teenagers and young adults (because the intervention was IT related and possible adjustment issues for this age group) who are told they are well and discharged from hospital. Trial information would be given at final consultation with oncologist.

They would be assessed for adjustment difficulties at baseline: HADS, EORTC, WOC.

Randomised, then follow-up at 3- and 6-months, repeat measures.

Patients would be given training on how to use a palm-top PDA, with which they could navigate themselves through a web-based programme (online information / CBT). They would be able to navigate through this process and levels of support based on their own perception of distress, i.e. stepped care dependent on their assessments.

DRAGONS' QUESTIONS / DISCUSSION POINTS:

This group of patients already followed up quite a lot and long-term (active follow-up)?

Will you pilot acceptability?

What if a patient was really distressed?

Would it be for all survivors?

What are the best measures to use with adolescents?

Is this the best time?

Trying to do too much all at once?

Control group? Offer similar interventions / access to information on the internet. The PDA might have a novelty effect in itself.

DRAGONS' DECISIONS:

Peter Rainey: IN

Lucy Wall: OUT

Gordon Murray: OUT

Neil Aaronson: OUT

GROUP 2: Sex in the Community

Group 2 presented a pitch for a couple's intervention focusing on sexual psychological distress after cancer.

Group conceptualises sexual psychological distress as having 5 dimensions: Intimacy, communication, activity (sexual), anxiety, and fatigue.

Dyads would be assessed at interview following first line treatment, would receive 3 x therapy sessions, and be given homework to complete.

This would be a complex intervention delivered by a health professional. The intervention content would be based on interpersonal therapy using Masters and Johnson techniques, and grounded in the patient's reported problems.

In this development phase, the intervention would be delivered by an experienced sex therapist. The vision is that in the future it would be implemented by upskilled health professionals in primary care / community based.

Soft outcomes: intimacy, anxiety

Hard outcomes: sexual quality and quantity

Outcomes would include self-reports of both members of the dyad.

Intervention development process:

- (a) define problem, develop measure
- (b) pilot and refine / feasibility
- (c) procedure / implement

DRAGONS' QUESTIONS:

How will you evaluate this?

What is the prevalence of these problems in general population?

Do patients want help – needs assessment, would anyone want to come?

Why not just go to Relate services?

How can you be sure the origin of these problems is not endocrinological dysfunction?

Is it too broad a problem and broad a group of people to give the same intervention? Heterogeneity – lot of variation in patient, problems, problems pre-cancer, range of intervention etc.

What is the best time to deliver this intervention?

Do you think you can engage men in this type of intervention?

How will it be delivered?

DRAGONS' DECISION:

All not in.

Concerns: Not innovative. By-passing specialists. Won't get people in.

GROUP 3: Brief Intervention to elicit patient concerns

Group 3 pitched an idea for a very brief intervention delivered from primary care.

There is evidence of effectiveness for this intervention in primary care, but it hasn't been shown in a cancer context.

The intervention is brief, inexpensive and innovative. It is for disease free patients who have completed treatment within the last 3-months. The intervention would take place within primary care when specialists carry out their end of treatment care plan and transfer over to the GP. GPs to contact patients within 3-months of discharge.

The intervention would be to change the wording of a question given by GPs at the end of their consultation. The wording would change from 'Do you have *any* concerns?' to 'Do you have *some* concerns?' GPs would be sent a training DVD of just 5 minutes. This technique has been trialled in America and patients expressed more concerns (which has been linked to reduced distress).

Assessment pre-consultation, then immediately after, 1-week and 3-months later.

Process outcome: number of concerns expressed.

Primary outcome: immediate level of anxiety (STAIS)

This technique could be evaluated in a cluster randomised trial. Trial methodology by region, controlled for deprivation levels.

DRAGONS' QUESTIONS:

How will the GPs be trained?

What about using different words such as many?

Would all GPs sign up to it?

Perhaps more important element is the GP call – and be more interesting to test the difference there. Important change is the GP phone call not the word, perhaps look at the rest of the content of the call.

Interesting area to focus on: One step / small change could have a cascade of effects?

What is the clinical relevance of this?

Think about how this fits in with pathways and clinical guidelines.

DRAGONS' DECISIONS:

Gordon Murray: In

Peter: In/Out

Lucy: In/Out

Neil: Out

GROUP 4: Return to Work

Group 4 pitched for an intervention to encourage patients to return to work, viewing getting back to work as a proxy for psychological distress.

The intervention would be for cancer survivors who have completed anti-cancer treatment, have a good chance of 5-year survival, and wished to return to work. Idea that this intervention could be prevent distress.

The intervention would tackle cognitions and barriers associated with return to work. It would be delivered by more experienced therapists initially, and then move towards training oncology nurses and possibly even expert patients. Delivery would be in the community and possibly over the telephone.

1st stage in development would be a proof of principle trial, then roll out into a bigger effectiveness trial.

Outcomes: primary - time off work, secondary - adjustment.

DRAGONS' QUESTIONS:

What about those patients who don't wish to return to work, isn't that the problem?

Need data upfront about what the problem is, i.e. age groups, prevalence etc.

What barriers are there that you'll deal with?

Is there a window of opportunity to get people back to work?

What is the optimal time to return to work? This is Influenced by a lot of factors. Also depends on the job the person is returning to.

Need to identify target audience more.

Needs qualitative study first to learn some theoretical lessons.

How does this fit in with the legal framework and benefits scheme. Fit in with government plans regarding incapacity benefit.

The outcome of this intervention is important to individuals and society as a whole.

DRAGONS DECISIONS:

Gordon, Lucy and Peter: Out

Neil: In

5. CLOSING DISCUSSION

Feedback from the Dragons on the afternoon:

Gordon Murray

There was a major focus on cancer survivors.

Many groups did not follow the 'ideal' line of developing and testing interventions.

Many groups focused on heterogeneous populations, which can often lead to null results.

Peter Rainey

Impressed by the projects and ideas.

It is important to focus on emotions early in the disease process.

A simple intervention is appealing.

Lucy Wall

We shouldn't forget the people with poor prognosis and how their family returns to normal life following bereavement.

Normalisation instead of pathologising is important to avoid stigmatisation

No need to reinvent interventions for problems that are not cancer related.

Neil Aaronson

Surprised by the emphasis on survivorship and primary care.

Little mention of the multi-disciplinary team.

There's already too much pressure on GP's, how do they cope with such difficult questions?

Following the 'ideal' line of developing and testing interventions is not always feasible, often due to the more pragmatic approach required by the funder.

No interventions focused on cognitive functioning.

The appropriate timing of interventions is extremely important.

General discussion re: Palliative care research

It's hard to find interventions that are pure (amongst others due to CAM: everybody is on something; e.g. aromatherapy).

The optimal timing of interventions is before the terminal stage as in the latter it's hard to assess anything in a reliable way.

Heterogeneity of care is enormous in end of life research.

New innovative ways of overcoming part of the problems mentioned were:

'Dynamic Technology Assessment' (when an environment is unstable and technologies are developing as well) or 'realistic evaluation'.

Next Steps

The possibility of a residential 'hot-house' was discussed, whereby groups would be given a similar task of designing interventions and would then move around expert workshops to develop ideas. For example: statistics, measures, intervention, delivery, oncology, user-involvement, primary care, psychiatry etc. At the end of an allotted time (e.g. 2-days) ideas would be presented and proposal(s) taken forward.