Damage and Repair.

10 years ago a friend Dr Josie Butcher looking at my work and was interested in the language I was using to create pieces around social and cultural ideals of acceptable behaviour. As a GP and psycosexual relationships she was working to giving her patients a voice to help repair the damage caused by of sexual cancers and the effects of its treatment. Working together on a project we found new ways of visually exploring relationships and emotional attachments. these ideas. Together we thought there was potential to join up our skills and work towards a project in her profffesional environment. Evidence was pointing to a need to develop communication skills of professionals , to enable patients deal with the trauma of their disease and treatment. Evidence shows

Macmillan (2006; 2008) looks at survivor issues recording more than 45% of survivors recognizing that emotional aspects including depression, anxiety, sexual and relationship impacts are the most difficult to cope with, and 48% feeling that emotional needs are not looked after in their care. Prostate Cancer UK patient survey 2010,

Evidence suggests 35 to 50% experience sexual dysfunction resulting from the disease or treatment but some studies with groups such as Breast Cancer show 70% of women experiencing problems. (Panjary, Bell & Davies 2011)

One of the most sensitive questions which arises in cancer survivorship is what happens to the sexual relationship.

Cancer patients have considerable difficulties with sexuality, body image and sexual expression. And emotional wellbeing. This impacts on both the relationship and social context (their work place, friendships and hobbies) in which people live their lives (Butcher 1999; Cottle 2003; Weeks and Gambescia 2000, 2002).

“ It also found that there was a need to help health professionals feel confident in talking about emotional and physical side effects” Other studies including the American Cancer Society Survey support these findings (Forbat, White et al. 2011; O’Brien, Rose et al 2011; Burg, 2015)

With this information and recognising a neeed we formed a group ComMA – communication Medicine and Art, 3 textile artist , a designer and Dr. Butcher

What we do.

We present art textile pieces at international conference on Sexuality and Cancer, for health professionals and encourage debate around the difficulties of communication in relation to a range of emotional issues

We disscuss ways trough their engagement with the work produced, how they could develop their skills when talking to patients about the damage caused to their emotional and sexual function. For the professionals it is part of CORST – professional development a compulsory part of their ongoing education

Grief, loss, difficulties of self image, survivorship, difficulties with relationships due to illness or treatment including sexual problems,

The research is undertaken at

International conference Sexuality and Cancer.

Artist own response from discussion, and information from Dr.Josie Butcher –Consultant Director of Psychosexual Health and Medicine

International Conference Sexuality and Cancer – Prostate Cancer

Artists response to a Focus group of cancer patients who were also educationalists and their response to the finished work.

Supported by Prostate Cancer UK

International Conference Sexuality and Cancer – Breast Cancer

Artists response to focus group of patients, development of ideas and process whilst the work is under development with the patients, shaping the ideas through dialogue.

How we do it

* we challenge our own preconceptions around the issues.
* We develop work using the language of Textiles which can be seen as exclusive to its practitioners.
* the work relates to the area of expertise of the viewers ( the health professionals) but they lack the knowledge to understand the pieces.
* The health professionals have to ask questions to understand work
* Learn from this exchange
* Gain confidence
* Learn and understand another vocabulary,
* How this experience can be taken back into their practice

ComMA’s role to challenge this is to enable health professionals and the patient to develop a ”dictionary” that breaks the barrier, and a more confident discussion to take place relating to the emotional and physical needs of the patient..

Textiles is our start but it opens up lots of other language references

Why we use cloth / textiles

Cloth / Textiles are loaded with many different cultural constructed meanings.

The first and last material to touch the body,

A marker of occasions a signifier of status and

Holder of memory

it can be transformative of ideas that go beyond the clinical and can resonate with a deeper sense of haptic or touch and emotional meaning.

Textile artist take this familiarity creating work with an emotional construct.

The language of medicine is mirrored by the language of textiles – known / familiar

a fact or action in the medicine -

Materials are cut, stitched, excess removed, repaired cleansed , contain and hold, repel and absorb, tear and stretch, marked out for procedures constructed and deconstructed, stretched, transfer and secure.

These attributes are used within the construction, choice of materials and process to make the work. This creates meanings in the work that can talk about

Uncommon / specialised language

The final challenge for the health professionals

The delegates view the work with a minimum of context.

Assess and try to understand what they see,

Read a context about the piece and question the pieces further

Discuss the work with the artists and find questions to learn more about the work

Answer evaluation forms and make statements about their findings.

Reflect on their experiences

Each artist takes a theme relating to the emotional difficulties of the patient

Amanda Clayton :

Prediction - Emotions of potential diagnosis.

Clayton worked directly with a patient, who had not spoken to his partner about the issues he was facing and the fear he was experiencing. He identified with her the following fears

* A need for control and stability within the Challenge on waiting for diagnosis
* A sense of Confusion and Invasion
* The agony of Unpredictability

Through starting to communicate his fears, Clayton was able to establish that a veichle for emotions could be referenced through an object that expressed his feelings. The wallet was established as this veichle. It fitted with his notions of it as a private object, a signifier of money, the provider, and male power , that could be lost,

An object that could close and hide information, something that was being involuntary opened to expose his emotion fears, he wanted to be able to close it at will .And he dreaded the Confrontation of imperfection were he to be damaged by the cancer.

This communication underpinned Claytons process describing how” the essence of cloth and its properties when constructed in relation to the uncertainty of the testing procedure prior to diagnosis “ the pieces were constructed to have Stability and instability through weighting forms that caused inballance or collapse or deform the shape. Multipule sectional pieces allowed to open and close dependent on the external force of weight. Edges often floundered or were tangled creating a sense of insecurity and confusion.

The viwers of the work were asking what was hiden and why? Questioned the unstable forms weighted down and heavy.

Dr. Josie Butcher worked with a ptient with reference The Clinical Relationship after Surgery, the damage caused by power differential, Conformity to Stereotypical Gender Expectations and loss of. The way forward and the repair to his very low self esteem, and difficult relationships was by talking in equations and Dr. Butcher making work about this.

Patients wait for lead, professionals may struggle to broach the subject, so finding the words and language on both sides is important. Together they created a manual of codes and equations.Thread Types of thread and stitchwere part of the coding part of coding Regularity / irregularity, varying tension, loose treads and tight.

Upper and lower case

Colour red – dark thoughts

Surgeon + oncologist+ Radiotherapy (me – prostate) =

Life – (desire + closeness)

The handkerchief paper or linen cancer has no boundaries – paper handkerchief can been thrown away or concealed in pocket – “discussion is like it is a throwaway, it will pass”

Elizabeth Couzins Scott

“Nobody Tells you how it will be” her patient said in response to his awareness of

Media Sexualisation, Gender Stereotyping, when trying to cope with Difficulties in his relationship, certainties falling apart” Researching the Definition of gender in the media difficulties in relating to this – sexual nature of celebrity and consumerism cousins scott worked on fragmenting images of female beauty and male attractiveness, using an army coat a signifier of male strength and stoic adherence to the job, was turned inside out with images pierced onto the cloth.

“ Our societies view of talk of balls of steel. Millions of euphemisms wrapped up in fertility, erections, and testicles that define a man, women borrow them the terms to describe toughness, I am still a male but not by societies immediate measure”

A Jamacian patient at the conference who was a sexual health worker with Jamacian men her and in Jamacia, responded to it as a valued piece of work. It would help in show a groups of men in his health care initiave to support them in being tested and raising awareness, the piece has become a valuable piece of textiles to talk around the difficult issues with this social group who have a strong macho culture and need other forms of approaches to their wellbeing

Angela Atkinson,s patient was angry and articulated “I am frustrated that I maintain a high sex drive but I am unable to express this physically. I am frustrated that no one explained the loss of size, the change in shape , the loss of hardness”, Maintaining a physical Relationship after surgery is problematic, the damage in many cases can be repaired to some level but requires a lot of “ embarrassing” discussions and needs a sensitive or upbeat practicle approach to support. Raw mundanity of the paraphernalia was displaid alongside the tools of a ceramicist. This evoked much discussion around the similarity of tools for the job, just different conditions and was much enjoyed by the health professionals. Alongside this was The fragility of the sexual System Negative emotional Space that remains Sense of “diminished / loss of manhood”. Casting the tools of the trade in plaster, creating a lace like structure in fine porcelain within the mould , and firing the piece which reducesthe form by 14% of the original size creates a very strong image relating to the patients feelings. The health professionals again wanted to interact with the work. Seeing a metal box they wanted to know what was in it, just more tools of the trade. A GP asked if he could put a penis in the box, amused the audience watched him as he closed the lid. That is what many of my patients do. I need to have something like this to show them.

The final piece is a work I made in response to the patients difficulties around “ Continuing an emotional and physical attraction and attachment to the one you love” the sadness of the statement and the distance that was emerging around relationship was explored in a piece called Separation

Alienation and isolation from the one you love

Bedroom chairs Love chairs Arm chair

referencing the comforts of home

“Frustration and alienation I pushed those closet to me away, I felt isolated”

The work has been used by St. Lukes Hospice for chidren , being used as part of their publicity around Teenage ( being up to 25) sexuality and Cancer

1. On looking at the exhibits I made assumptions about what the exhibits were trying to communicate based on my own thoughts about the exhibit.

completely very much quite a lot a little bit not at all

1 4 9 13 2

2. I understood what the exhibits were trying to communicate without needing to look at the expanded text.

completely very much quite a lot a little bit not at all

0 3 8 14 4

3. I learned more about what the exhibit was trying to communicate by reading the expanded text (listening to the artist’s / patient’s words).

completely very much quite a lot a little bit not at all

7 11 9 3 0

4. The exhibition made me think about the complexity of communication.

completely very much quite a lot a little bit not at all

9 12 3 6 1

5. The exhibition highlighted patient issues that I should consider as part of my role.

completely very much quite a lot a little bit not at all

10 10 3 5 1

6. The exhibition made me consider the need to discuss sexuality in greater depth with patients.

completely very much quite a lot a little bit not at all

13 7 3 3 3

**Delegate comments;**

**Any Comments on anything that surprised you in the workshop?**

The depth of meaning.

My own perception was very different to what it was said about each piece of art.

How emotional I felt. How I wanted to meet the focus group members and ask more.

Loved the use of male iconography – jacket, handkerchief.

**I was unwittingly only looking through oncology eyes. Listening to the artist extended my gaze and the booklet was a lovely confirmation and challenge.**

**How much I was made to think of the fragility of human experience.**

When spending time looking further at loss, I felt this tapped into my own sense of loss.

How powerful Art can be in portraying a message.

**Sad. I need to talk to my patients more.**

Inadequate.

Shock, sadness, hopefulness.

What an excellent way of accessing important information.

**Need to challenge my own superficial assumptions. This should be transferred to the therapeutic experience**

Very thought provoking.

Emotional, excited, curious, amazed, greedy for more.

Made me think of men differently.

It identified to me how delicate some patients are when diagnosed with prostate cancer.

Increased consciousness of the issues.

The experience will stay with me. It did challenge my thoughts on communication

Thought provoking, how important to pay more attention to our non-verbal communication.

**Never assume anything**

Made me think about misinterpretation.

**How did you feel experiencing this workshop?**

**This experiential workshop counted towards your cpd points for the day. Did you find this approach to learning valuable and / or interesting? Did you enjoy it?**

Interesting. I was challenged by it.

Both valuable and interesting.

**Yes, it deepened my understanding of the complexity.**

Very interesting and thought provoking.

It definitely helps with Reflection.

**It was an experience of self-reflection, quite a speedy way to access deeper meanings**

It raises questions and interesting working to challenge and learn

Helps to recognise that feelings and ideas can be represented in different ways.

A valuable experiential counterpoint to the didactic aspects of the day.

A different slant on learning, perhaps a deeper impact than academic learning alone.

Stretched me to connect with visual imagery as opposed to dominant reliance on language.

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Papers have been presented

Feminism and Design Activism, - Royal College of Art

Communication Medicine and Art – Kings College London – Midwifery and Obstetrics

Symposium, - What can I do to Make it Better? Damage and Repair – University of the Creative Arts Farnham March 2016

Presented Exhibition and research at 2 International Conferences - Sexuality and Cancer / Sexuality and Cancer – Prostate Cancer

Presentation and Research - International Conference on Sexuality and Cancer – Breast Cancer winter 2016