Dying for Sex: why we need to consider sex and pleasure as part of palliative care.

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"The person I get the gift of falling in love with when I die is myself." — Molly Kochan

'Orgasm with another person!' – this is the celebratory refrain from a 'bucket list' in the recent Disney+ dramatization 'Dying for Sex', based on a podcast (1) which tells the real story of Molly Kochan, diagnosed with terminal breast cancer in her 40s. In the show we see the transformative potential of having the right support to pursue sexual aspirations and pleasure during palliative care and serious illness. We may also note how radical this pursuit seems to be, not only in the context of cancer stories and palliative care but in wider aspects of life where people, especially women and gender minorities, are discouraged from seeking and claiming the sexual freedoms that they would like.

Background: Think Universal

We know there is a widespread silence and stigma around sex and pleasure in general. For example, in a recent systematic review investigating sex life concerns and contraception, it was identified that pleasure is woefully overlooked, even though people stop using contraception when it stops them having the kinds of sex they want. After screening over 16,000 articles, only 2 studies were identified that directly addressed 'sex life concerns' like pleasure, in relation to contraception (2). Indeed, even though pleasure is arguably the key reason people have sex (3), it is very rarely factored into sexual health programming (4), let alone other clinical realms.

Wellbeing in relation to sex and sexualities tends to be conceptualised and operationalised in a 'pleasure deficit' where the risk and negative outcomes of sex are focused on and 'death, danger and disease' dominate (4, 5, 6, 7). This is despite recognition of the critical importance of sexual wellbeing and pleasure e.g., in the official definition of sexual health by the WHO (8); and the Guttmacher-Lancet commission 2018 (9). We also know that safer sex, sexual wellbeing and pleasure are extremely important for individual health and identity, have implications for gender equity and justice and therefore contribute to family, societal and global wellbeing (9).

The discipline of palliative care has an acute awareness of the need to enrich and enhance quality of life. However, like other domains of healthcare, palliative care most often overlooks or avoids sex and pleasure (10), a situation frustrated by social, interpersonal and physical impacts of illness e.g., as identified by research, shifts in roles between partners due to care needs and desexualisation, body image impacts and effects of previous treatment regimens (10, 11, 12). A recent scoping review about sexuality and intimacy in end of life and palliative care has identified how healthcare providers tend to deprioritise sexuality and intimacy due to a number of underlying drivers, for example, "paternalistic attitudes and judgment about appropriate versus inappropriate behaviour during end-of-life" (10, p387).

Increasingly, researchers, clinicians and campaigners are focussed on identifying solutions and responding to need in palliative care (13), as illustrated by recent publications in Palliative Medicine about sexual health at end of life and the impact of advanced cancer on sexual

relationships respectively (14,15). What is acknowledged is how little we know about sexual wellbeing in this area and what could be done to respond meaningfully to the needs of palliative care patients.

Understanding the cause of this pleasure gap: Rights First

The foundations of the sex and pleasure deficit are entrenched in histories of shame, stigma and power, and are related to what Gayle Rubin classically referred to as the 'charmed circle' (16). This circles identifies how certain types of sex are privileged and legitimated over others. In this frame, monogamous, heterosexual sex in pairs represents 'good sex'. This privilege can be translated to pleasure privilege where certain sexual identities or relationships having pleasurable sex is a cultural norm, such as married heterosexual men, while it is punished or stigmatised for others such as sex workers, queer people or people with a diagnosis or disability. Critiques of Rubin's original work note that sex is also regulated through systems of oppression such as sexism and classism (17), not just the type of sex a person is having. All of these aspects have relevance for sexual wellbeing in palliative care whereby sex when unwell or approaching end of life may be considered unfeasible, inappropriate, unimportant (compared to the 'serious business' of staying alive or dying well), and circumscribed by systems such as ageism and ableism (17) that reinforce pejorative assumptions that older people, people with disabilities and so on are not desirous (and desired) sexual agents.

Possibilities for pleasure: Love Yourself

To return to 'Dying for Sex' and Molly Kochan (whose priority was not how she was going to die, but how she wanted to *live*) the dramatization beautifully depicts not only a real life quest for sexual experimentation and pleasure for a person approaching the end of their life, but the crucial difference made by a practitioner's support to realise these experiences, through validating conversation in the first instance. Palliative healthcare providers, as advocates of a comprehensive and holistic way of considering and championing quality of life and person-led care, ideally occupy an ideal position in terms of supporting individual desires in relation to sex and pleasure. Where spiritual, psychological and cultural needs are routinely championed in care and support, why is sexual wellbeing, sexual relationships and pleasure still routinely left out as valid domain? There is a political power in pleasure, in visioning what a sex and pleasure positive future could look like, and how that makes us move further than 'good enough' or bearable.

We must also recognise that pleasure is diverse: it means different things to different people, communities and cultures and to engage with pleasure is to engage deeply with this diversity. In practice, qualitative research about implementation of pleasure based sexual health (PBSH) projects in diverse global contexts, in this case from India to sub-Saharan Africa (18), highlights how avoiding assumptions and attention to conventions of local languages when discussing sex and pleasure, are important. It also highlights how practitioners should avoid assuming certain communities *don't* want to talk about pleasure or are not able to, without checking that with them using the right conversational tools. Gender norms and inequity, along with differences in legislation e.g. that which criminalises same sex activity, are also featured as key considerations (18).

In the absence of robust research and interventions currently we can seek to borrow and build from other areas. For example, The Gynae Cancer Narratives project (12) identified how people who had been treated for gynaecological cancers wanted more support to address their 'sexual

side effects' and how fearful clinicians could feel about confidently offering this care. Work between researchers and radiographers led to the development of talking prompt resources to help support conversations with patients about sex in practice. These outputs map onto 'Pleasure Principles' (19) from campaigning organisations like The Pleasure Project who have been working since 2004 to advocate for the integration of Pleasure Based Sexual Health (PBSH) across diverse fields, including through activities to help start conversations about sex and pleasure (20). With an emphasis on inclusive language that does not make assumptions about types and function of body parts or sex, and available in English and Spanish language, this guidance presents an ideal foundation to consider sex and pleasure in the context of palliative care.

Recommendations for research: Embracing Learning

Palliative care's commitment to meet the holistic needs of patients makes imperative the need to proactively acknowledge and integrate an understanding that sex, sexuality and pleasure is a core need for many people. As a 'flagship' sector for patient-centred care, palliative care has the potential to drive a transformative shift in broader healthcare in relation to PBSH. We suggest, for practice, a goal of embedded and routinised PBSH thinking across palliative care practice and to build an understanding of its importance and centrality in person centred care, in parity with other palliative care values.

To achieve this we recommend a research agenda that involves taking a multidisciplinary and affirmative approach cognisant of inequities in healthcare systems e.g., for resource rich versus constrained income contexts, patients with comprehensive insurance versus those with limited insurance access, or no insurance, and how these dimensions factor into the 'charmed circle' of who is entitled to claim sex and pleasure a part of their palliative care experience. We recommend building an evidence base grounded in patient experience, using a lens of equity and justice, and embracing a theory driven approach that means evidence generated is transferable across diverse country and cultural contexts. We need research informed tools for healthcare workers to facilitate conversations with patients so they can express themselves without shame, and to feel comfortable to discuss their sexual needs alongside their other needs. Sexual Wellbeing and pleasure are not routinely covered in medical training and require knowledge on how to ensure staff feel confident and can have conversations with ease.

Ultimately, we hope to inspire research that can inform the development of a disciplinary culture in palliative care that embraces a vision in which people's safe consensual desires and achievement of sexual well-being, in the fullest sense, are valued, normalised and celebrated on the same level as so many other aspects of being human-where we have capacities for multiple pleasures through our lives, and as we die. We all, like Molly Kochan, deserve the space and ability to prioritise sexual exploration, claim pleasure and exercise our sexual autonomy as part of a palliative phase of life.

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