

Rethinking Palliative Care and Public Health Services in Urban Indian Context

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Article History

Received: 22.11.2017

Accepted: 27.11.2017

Published: 30.11.2017

DOI:

10.36347/sjahss.2017.v05i11.027



Abstract: The pioneering works of Cicely Saunders 1960s onwards made Palliative Care (PC) and hospices embrace the end-of-life care needs of patients across the world. In 1986, World Health Organisation defined palliative care as the ‘total active care’ of patients who is not responsive to curative treatment. However, the improvement in anti-cancer treatments and technology enhanced survivals rapidly and made PC more inclusive. WHO radically redefined PC (WHO 2002) as ‘an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness (...)’. Although some gaps in palliative care recently surfaced for interdisciplinary research and loosely highlighted in India comprise my research area, through this study, I tried to understand the lived experiences of cancer and how people talk about their illness and treatment experiences, what are the usual problems does one face in this context and how it can be addressed. The data was collected using semi-structured, in-depth interview schedule from purposively selected participants. This phenomenological study was undertaken in a govt. hospital and in a private nursing home of Kolkata, West Bengal; and the collected data was transcribed verbatim to include insider’s perspectives and the findings were organized under the following themes- (i) effective-yet-multiple constructs of care, (ii) in-situ mutual and co-constitutive training, (iii) qualitative research-as-therapeutic care-service, (iv) empathic identifications of PC problems and feasible recommendations. The nature of the content the current article is descriptive, specific and subjective, which tried to understand caregiving from a qualitative perspective and emphasises that qualitative methodologies may be beneficial in enhancing the capabilities of palliative care and subjective well-being.

Keywords: Palliative Care, Qualitative Research, Cancer, Carers, Well-being, Resilience, Semi- Structure interview and story-telling

INTRODUCTION

The pioneering works of Cicely Saunders 1960s onwards made Palliative Care (PC) and hospices embrace the end-of-life care needs of patients across the world by two and a half decades [1]. In 1986, World Health Organisation defined palliative care as the ‘total active care’ of patients who aren’t responsive to curative treatment. However, the improvement in anti-cancer treatments and technology enhanced survivals rapidly and made PC more inclusive (for many other illnesses and its onset before treatment). Later, WHO radically redefined PC (WHO 2002, emphasis/italics added)- “an approach that improves the *quality of life of patients and their families* facing the problem associated with *life-threatening illness*, through the *prevention and relief of suffering* by means of early identification and impeccable assessment and treatment

of pain and other problems, *physical, psychosocial and spiritual*” [2].

In 2014 statement, WHO mentioned ‘*no ... limit on the delivery of palliative care*’. It added emphasis on universal human right to palliative care and enhanced *Quality-of-Life*. WHO started utilising core skills (e.g. pain control, symptom management, bereavement counselling and person-centered care that includes the family) to make PC appropriate in all settings and through an interdisciplinary team approach.

In India (2012), of approximately 908 palliative care services through home care, outpatient basis and in patient service, around 95%, are in Kerala, thereby making access to quality palliative care services

extremely limited for the vast majority of Indians [¹]. The expert committee in their Proposal of *Strategies for Palliative Care in India* (2012) responds to the situation with the prior objectives of (i)improving the capacity of the service;(ii)refining the legal and regulatory systems of proper medicalisation; (iii) encouraging attitudinal shifts amongst healthcare professionals; (iv)promoting community owned initiatives supporting health care system; (v) continuously developing national standards for palliative care services;(vi)emphasizing the same in private health centres. Following WHO guidelines, the committee set the above six prior objectives which are very basic for its huge population in need of PC.

Today, medical professionals along with palliative care teams provide good medical treatment, by alleviating pain, treating symptoms, communicating with patients and their families, allowing volunteers to help and really try to individualize the care provided according to the patient's needs. But there are still barriers and gaps in palliative care, which on occasion pit the dying patient on one side and teams of professionals on the other side. Many social scientists, including anthropologists, health psychologists and psychosocial oncologists, have proposed and developed a diversity of prescriptive ways of defining how to 'cope with cancer' and what is the 'meaning' and 'experience of illness', 'experience of suffering', 'experience of care' and 'experience of dying' is for the patient [3,4]. However, few have considered the problems people in individualizing needs of palliative care (including the patients and their family caregivers) and people around them might encounter or how and what they have to actively manage in social interaction for enhancing well- being. However, some vital gaps of premises of PC recently surfaced worldwide for interdisciplinary research and never highlighted in India comprise my central focus, i.e. the basic unmet intervention in relationship between the performances and wellbeing of the professional health carers (e.g. public and NGO health workers, nurses, doctors etc.) and the experiences of satisfaction and wellbeing of the patients and their family caregivers through PC. The perpetual growth of PC principally depends on the societal-cultural and organisational contexts within which *inter-personal, networked, transactional, functional, emancipatory/empowering* relations of care—between health care professionals and patients (including their families)as well as between care professionals—occur. I have tried to fulfil the serious

lack of multi-method, interdisciplinary approach to PC, by combining phenomenology, and discourse analysis—about the experiences of cancer lived by the patients and their carers attending one public and one private hospital in Kolkata.

OBJECTIVES

I tried to cover the following research objectives: (i) effective-yet-multiple constructs of care, (ii) in-situ and co-constitutive training, (iii) qualitative research-as-therapeutic care-service, (iv) empathic identifications of PC problems and recommendations.

METHODS

Primarily being concerned with phenomenology, I purposively selected cancer patients and carers (n=10) and they were interviewed, after gaining informed consent, using semi- structured interview schedule. The study was undertaken in a private nursing home and in a govt. hospital in Kolkata, West Bengal. The collected data were transcribed verbatim to include insider's perspectives; the transcriptions of the interviews eliminated names, characteristics, and any individual ways or expressions that identified the participants. And the findings were organized under the following themes-

FINDINGS

The Themes according to the Objectives Effective- yet-multiple constructs of care

Palliative care professional deals with the symptoms that effect the patient and their family, specifically, the specialists manages fatigue, breathlessness, anxiety, stress and depression [5].But Palliative care shouldn't be only about the management of symptoms, physical and psychological needs but also about the subjective; individual needs We need to concentrate on the subjective aspects of care and need as the patients (and their families) for varying background, might have varying needs, and furthermore needs and requirements tend to be relative; for instance, in case of Priya [²], emotional assistance is more required than the technical aspects; while for Mala [³], emotional assistance is likely necessary.

Similarly, some of the participants seeking treatment from govt. hospital stressed on an 'enabling environment'. For instance, Asma, whose daughter is suffering from blood cancer, said- *...you see it yourself... we all are quietly sitting here... thinking about our plight... no one talks with us... just the doctors... and sometimes other patients... (Asma).*

¹Directorate-General-of-Health-Services, Ministry of Health & Family Welfare, November 2012:

http://palliumindia.org/cms/wp-content/uploads/2014/01/National-Palliative-Care-Strategy-Nov_2012.pdf

²Priya is suffering from cancer,(she didn't know the details of her diagnosis) for the last four years

³Mala is a 65 years old women suffering from uterine cancer.

While, few participants were worried about the infrastructures, and considered that an improved setup of public health care system would greatly help in enhancing their well-being. Sunil⁴ said- *...as you can see here, there is no separation between the bed, nor individual space neither individual facilities... you can't have any privacy ...*

Simultaneously many were upset about their physical conditions- the pain, side-effects experienced, both from the anomaly and the medical procedures.

While almost every one desired for a friendly attitude and behaviour from the care providers.

I was scared to talk with them (nurses)... they always scold us... I have never seen them talking politely... why they act like this... still.... anyways... (Bapi [5])

In case of private health care services, the participants expressed concern about the behaviour of the doctors. For example, Sayani was very affected by it. For her, qualification and experience of a doctor is necessary, but she considered politeness and compassion, as vital characters of a doctor, especially in her case, where she is struggling with everything. She said- *...oh my god he [doctor] is a hell of a person... he has lot of attitude... he doesn't talk with us properly... for example, yesterday mother asked about the condition of my father and the possibility of release and the way he said it he hurt my mom... he roughly said- 'I would keep him here for 4 days and which day is it?' It was the third day... can't we ask about these things? You tell me, did we ask anything wrong?He is a learned person and is old enough, but doesn't know how to talk with others... he is good in his profession but is arrogant too... 'we' the patient party are already in agony and above that, this kind of behavior is really not acceptable... we go through so many things and now this too... I really don't like this type of people at all... he is here for us... but see, how he behaves... (Sayani [6])*

Thereby, it seems that the needs of the patients varies from setting to setting and from participant to participant; almost all the participants are worried about the physical needs, but with it, for some it's about the material aspects, the infrastructure of the institution, while for other few it's about the behaviour and the attitudes of the care-giver.

In-situ and co-constitutive training

⁴ Sunil is suffering from liver cancer for the past nine month. He has two daughters and lives in an extended family.

⁵Bapi's father has been diagnosed with oral cancer.

⁶Sayani's father is diagnosed with throat cancer.

During this study, it was comprehended that caring in a transactional process. When interacting with the participants, I realised their requirements, for example, Kartick [7], needed 'someone' – a companion, with whom he can talk, share his loneliness, feelings and experiences, and I understood his indications, and I behaved in that way, which made him feel good. While with Priya, I had to take the role of a guardian, who consoled her, and motivated her to be strong and to maintain her fighting spirit.

Thus, just managing the symptoms, relieving pain isn't sufficient. One has to recognize, the other aspects- the 'unsaid' needs of people with life limiting illness, which would be helpful in enhancing of the well-being of the patients and their relatives.

Qualitative research-as-therapeutic care-service

The use of qualitative methodologies, and in particular unstructured or in-depth interviews and story-telling has several potential benefits not only for exploring the experiences of patients, their relatives and healthcare professionals but also in facilitating a sense of well-being, to develop personal resilience and which in turn may have some therapeutic values [6,7]. In this research, it is apparent that, the sense or feelings of 'well-being' were associated with 'talking'. As the participants were free to express, talk about the issues they want to; helped the participants, especially the patients, to move beyond their illness, to 'escape' from their present experience and that in turn aided to their resilience. While talking with a stranger, the patients felt that they were being cared for and felt supported in a very personal way that sustained their sense of individuality. Talking, often helped the participants to relax, Soma [8] said-

...It helped me... talking with you... I am scared ... but... now... not so much... talking with you really calmed me down...

Talking about thoughts, feelings and issues helped them dealing with their situation, helped them in releasing stress. Sayani shared many intricate things about her life, and sharing those emotions helped her, from her narratives it was also understood that how much she valued being listened to; she said-

...how will I make you understand... the things I just told you, I could say it only to you ... don't mind ... as you are a stranger I know you won't judge me... I have seen the state of my family when I was just in class X, how everything changed... how I have changed... now, I have to do so many things... I have to manage my life as

⁷Kartick is suffering from prostate cancer for the last eight months

⁸Soma is 34 years old housewife has a son and daughter, diagnosed with breast cancer 12 years ago and had double mastectomy.

well as to take care of every one ... but no one is there for me... I don't know how I am managing all these... and as I am elder, lots of expectations are there... it's okay I can take responsibility... but sometimes I get so frustrated with my life that I want to leave all this and go somewhere else... I have to console every one specially my mom and sister... but who is there to console me... who will say to me that 'I am there and everything will be alright'... I am really upset with my situation.... you know the main problem is that I can't express my irritation, my frustration, my pain to any one... except my best friend... boyfriend...and you now... but sometimes I don't tell him everything... he is having problems of his own... he too is frustrated...I need to vent out all this... I am a human being after all ... and after telling you so many things, I feel relieved... I know you can understand me...

Like Sayani, Kartick also expressed a need of a stranger to share his privacy -
...you weren't there yesterday... my wife came... I told her about you..... (Kartick)

Similarly, talking facilitated a way of being with the patient that helped the participants to cope with what they were facing, helped them to find meaning, to make sense of the resultant changes within their life. Participants felt good after the interview, after sharing their thoughts and emotions with me, they said-
I want to tell you so many things... and ... it's really difficult... I have never talked about this with any one... not even with my friends... but it feels good... letting all these things out.... Earlier I didn't think about talking about these things... more over I don't have anyone, with whom I can say all these ... whom I can trust... who will listen to me... will understand me and more over won't judge me or make fun of my emotions... (Bapi)

Furthermore, spending time with me, made them feel as if 'I am a part of them', someone who is very close, which gave them a sense of security. The intimacy grew so much; that they began caring for me, my health, introduced me to their family, and others, and Soma even introduced me as 'her daughter' to the fellow patients.

Thus, qualitative research has some potential to enhance the well-being of the patients and their relatives, instil a sense of security, individuality; through listening to their stories, which in turn give validation to their experience and sometimes is helpful in gaining new perspectives; as well as promote personal resilience, thereby contributing as therapeutic care services, although further exploration of this aspect is required.

Empathic identifications of PC problems and recommendations

Though PC is specifically concentrated on the relieving pain, managing distressing symptoms and enhancing the quality of life of the patients and their family members, but there are few aspects, which are overlooked, such as the emotional well-being of the patients and their relatives.

From the narratives of the participants, it is evident that uncertainty and anxiety was most common amongst those who are diagnosed with cancer and among the family members of the patients. The participants were mostly uncertain and worried about the future; about their and their family's future. Generally, the patients were very ambiguous about their condition; their health and their treatment. For example, Sunil was uncertain about his future. He was much tensed about his health and his treatment; about its effectiveness-

...I thought and planned so many things... but now... everything has changed... I don't know what's next... what's going to happen with me? Will I be fit like I was before? Will this (chemotherapy) work! Will it be cured!!

Likewise, the relatives were also uncertain about their future- about how everything will turn out or how they will manage the situations. For Bapi, dealing with cancer is very tough, He is so troubled that he can't think beyond his situation, about his future, and even if he tries, the miseries of his life pins him down-
... I don't know what is waiting for me 'out there'...Whatever I am going through is very 'tough'... I don't have a life any more... I seems like I am just living on... on and on... don't mind... you guys are thinking about life; your future ... but when I think about my future...I see nothing.... there is nothing.... nothing...for guys like me... at this stage, we think about settling in our life... but I don't know, would I be able to lead a normal life? Would I even get married! and even if I want to settle down, I have to do lots and lots of things... have to start from the scratch... will it be possible! Don't know...

Almost all the participants were concerned about the survival of their family. The patients, who are parents, are concerned about the future of their children, specifically, after their death, while the others were vague about the maintenance of their family due to the financial strain that has incurred upon them from treatment of cancer. The participants also expressed that they were drifting away from their usual relationships with others. They mentioned about a growing distance between them and their relatives. Kamala is very affected by the distance between her and her daughter, she said-

...actually... from the moment she (her daughter) came to know about my illness... she is behaving differently... she doesn't talk with me much ... I think she isn't feeling good... she is hiding her feelings, which is affecting her and I can't do anything about it...

Both, Ruma and Bapi, revealed how lonely they are now, how they have to sustain everything all alone, they said-

...no one helps me...no one is there for me... my father has abandoned us... and I have a brother who is busy with his wife and children...he left us... (Ruma)

...before all these; I was a normal kid with lots of friends... who used to gossip and roam around... but now I have none... my life is totally different...full of responsibilities... (Bapi)

Thus, this analysis describes the way that participants experiences uncertainty, fear, isolation and a 'sense of having no bearing from which to navigate their lives'. It illustrated their changing concerns, with varying intensity, and draws the attention towards a vulnerable condition which requires immediate actions.

CONCLUSION

Based on the discussions outlined above, it is recommend that using qualitative frameworks or research on terminally ill individuals, i.e. palliative patients and those approaching the end-of-life, not only magnify the sensitive issues about the needs and care of the patients and their carers, but will also contribute to the physical and emotional well-being, of patient and their family members. Thus, this endeavour was an attempt to show how qualitative research can complement the palliative environment and the quality of life, with research interview and/or story-telling becoming therapeutic for the participants, as it enables cathartic, affirming and reflective aspects of disclosure in a safe and supporting milieu. However, there are several matters which should be taken care of, such as, the researchers need to be aware of power relationships between the participant and the researcher, not only as it can bias data but could also be detrimental to palliative and end-of-life participants. In doing so, researchers should reflect on the dynamics of their interaction with the participant. and thus we stress that there is a need to consider these issues carefully on a case by case basis, rather than adopt a one-size fits all approach across their portfolio of work.

We believe that this effort will be helpful in understanding the dynamics of care and care-giving, the less explored aspects of subjective well-being and the necessity of incorporating qualitative methodologies in enhancing the capabilities of palliative care, though exhaustive researchers are required to examine how to better supplement palliative care and quality-of-life using qualitative methodologies.

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