



## Starting a palliative care initiative using a transformational development approach

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### Introduction

His first eye had been removed at 4 months of age for retinoblastoma, and his second eye a year and a half later when there was a recurrence. Since there was no evidence of metastases, his family mustered what little resources they had to fund his chemotherapy. On completion, they returned to their rural home with hope. A year later his mother brought him to Malindi Sub-County Hospital with rapidly progressing swelling in his limbs, forehead, and the floor of his mouth. He was able to chew only bananas and drink milk and was hungry and in constant pain, crying and squirming. His mom was tired, stressed, and hopeless – for a long time there had been nothing she could do to make him happy or comfortable and neither of them could sleep. The pediatric intern asked the palliative care team for help and together, along with his mother, we agreed on a goal - to make him smile. The head nurse on the pediatric ward found it quite irregular to allow morphine to be given to one of her patients but she acquiesced. Three days later the mother was smiling; her son was improving. The morphine and dexamethasone were controlling the pain and swelling, and the Plumpy Nut malnutrition supplement the nutritionist had given him was satisfying his hunger. A few days after, I came across the mom feeding her son some ice-cream; he had a huge grin. Mom and son were able to forget about his illness and enjoy relationship and life together for the short time he had left.

### Palliative Care and Transformational Development Together

Palliative care and transformational development both involve a holistic approach to relieving suffering and in the process, improving quality of life. The focus of palliative care is relieving the suffering of the patient who has a life limiting illness, and also the suffering of their family. Transformational development involves communities as they struggle with the suffering caused as a result of sin in this world; this might be children dying as a result of the lack of clean, accessible water, or in this case, community members with life limiting illnesses living and dying in miserable circumstances.

The World Health Organization definition of Palliative Care is, ‘an approach that improves the quality of life of patients and their families facing the problems 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.’<sup>1</sup> A palliative care approach involves caring for a person with a life limiting illness, and their family, with the attitude of giving them the best quality of life by actively preventing and relieving suffering, whatever the origin of the suffering.

There is no universally agreed upon succinct definition for transformational development (TD). World Vision defines it as, “The process through



which children, families, and communities identify and overcome the obstacles that prevent them from living life in all its fullness.”<sup>2</sup> Bryant Myers, in *Walking with the Poor: Principles and Practices of Transformational Development*, uses the term transformational development to reflect his, “concern for seeking positive change in the whole of human life, materially, socially, and spiritually. . . . The transformational journey is about finding and enjoying life as it should be, as it was intended to be.” He describes it as “a process of change that affirms the joint roles of God and human beings, the need to focus on restoring relationships.”<sup>3</sup> But what does this process look like? Practically speaking, TD involves humbly walking along side of communities, building relationships with them, learning from them, helping them to identify their God given strengths and resources and use them to address the challenges they face, and at all times maintaining their dignity as image-bearers of God.

## The Rationale of Transformational Development

The theological foundation of transformational development is that God gave man, from the beginning, four areas of relationship – with God, with those around him, with the created world, and with man himself (Genesis 2). At the fall, each of those areas of relationship was marred (Genesis 3), but through Jesus’ sacrifice those relationships can be restored. Disease is a result of the fall, and so are the other strained relationships it brings. Today God is actively working to restore those relationships so that we live in joyful intimate relationships with Him, with others, and with the rest of creation, reveling in the dignity he has bestowed on us. We get to work with him when we address these issues; this is not our initiative, it is His.<sup>4</sup>

When seeking to start a palliative care program, how can a TD be approach be helpful? Firstly, when a palliative care practitioner is invited to a community to begin a palliative care program, unless they also have intimate knowledge of the

community’s resources, needs, or culture, they do not have the knowledge necessary to practice palliative care in that setting. There is no “cookie cutter” palliative care program that can be duplicated from one community to the next; each community is unique and it is through relationship building and dialogue that the community is able to determine their own needs. The TD focus on relationship building and the practice of Appreciative Inquiry provide direction for a strong beginning.<sup>4</sup>

Secondly, palliative care requires a multi-disciplinary team in order to meet the needs of patients.<sup>1</sup> Only the various disciplines themselves are able to determine what they can bring to the table and how they might integrate their services. The asset based community development (ABCD) strategy used by TD practitioners provides guidance for helping people discover how and what they can contribute.<sup>4</sup> Thirdly, people are invested in things that they have had a hand in crafting. If the ultimate goal is to have a locally integrated program, it must be birthed and owned locally.<sup>4</sup> The most detrimental stumbling block to effective community participation, according to a group of experienced volunteers in a successful community based palliative care initiative in India, is a strong hierarchical organizational structure with powerful people at the top, people who are hardworking and consider themselves indispensable.<sup>5</sup> Using the inclusive participatory “learning process” approach to development with its action-reflection cycle safeguards against such impediments of sustainability.<sup>4</sup> Lastly, TD recognizes that God has gifted the community to be able to work together towards meeting the needs of one another; this is His work and His responsibility. This allows the practitioner to watch the process and be amazed at what God does, rather than fretting about how much progress is or is not being made.

## Starting Palliative Care

How does one start a palliative care initiative? The World Health Organization suggests applying a



public health strategy to palliative care and identifies four fundamentally important components that need to be established if palliative care is to be incorporated into a country's health care system, namely adequate drug availability, widespread education, implementation through all levels of society, and appropriate policies to undergird the first three.<sup>6</sup> These components have been used as a framework for structuring a variety of successful programs, for example those reported in Mongolia, Jordan, and Nepal.<sup>7-9</sup> In these three cases the examples of addressing the four components are all very large scale and are from a national perspective involving ministers of health and medical training colleges, importation laws and quotas. While these specific examples are on a much grander scale than would be applicable to a small local initiative, the four components are equally as relevant for small fledgling programs as they are for national initiatives; in order for any palliative care initiative to succeed and grow there must be drugs available to control symptoms, education for all (for example community members, health care workers, public officials), there must be provision of services that are widely accessible, and when the need arises there must be policies that govern the services, education and drugs. These are concurrent activities, not sequential.

So what does it look like to combine the four components of the public health strategy with TD? It begins with listening and relationship building. In the West it is said, there can be no relationship without trust. In Africa, there can be no trust without relationship. In 2011, I was invited by the government hospital in Malindi, Kenya, to mentor the startup of their palliative care program. In the first months I often felt guilty because I was not busy seeing patients. I would see the patient or two who had been referred, then sit around the wards talking to nursing staff, interns, cleaners, pharmacists, the physiotherapist, the nutritionist; whoever was around. They would tell me about a family member who had died, a neighbor who was sick, or their own

passion to help those less able. I didn't feel like I was doing palliative care 'work'. But in retrospect those relationships, built by showing up every day, established trust, were a means of education, and opened many doors later in the process as staff grew to understand palliative care and were eager to play their part. A helpful resource for these conversations was the Palliative Care Toolkit, an excellent book available free of charge online in six different languages, written with the intention of assisting and encouraging fledgling palliative care start-ups, which suggests asking four questions (Appreciative Inquiry):

1. Who needs palliative care where we are working?
2. What are their main problems?
3. What help are they getting at present?
4. What could be added to improve their care and make it holistic?<sup>10</sup>

The combination of TD and the public health strategy for palliative care also involves teamwork and collaboration. As you listen and build relationships you will find people from a variety of walks of life with whom the concept of palliative care resonates. Most often they have experienced a significant loss or have a family member with a disability; look for some who could be members of a palliative care committee. Seek advice from those around you. Develop and maintain strong ties with the national palliative care organization. Learn from the nearest palliative care initiative – how did they start, how do they access (and mix) morphine, how can you collaborate, and what pitfalls should be avoided. Go with the cultural flow; if some are passionate about an activity that you are not, encourage them to run with it. Together, begin to address the four components of the public health strategy for palliative care: widespread education, implementation through all levels of society, adequate drug availability, and appropriate policies to undergird the first three.

How will you educate? Much of the education is informal and begins with simply raising

awareness. Speak about palliative care to anyone who is interested to listen wherever the opportunity arises, whenever there is an invitation; friends, service clubs, health care staff (both professional and support staff), as well as community health workers. Often informal conversations with the cleaner or the night guard will strike a resonant chord more so than with fellow physicians. As you speak with people they will speak with others and word spreads. Courses and seminars are also effective. The Palliative Toolkit Trainer's Manual comes in five languages with ready-made lesson plans covering everything from the definition of palliative care, teamwork, and breaking bad news, to how to prescribe opioids, providing spiritual care, and more; everything needed to teach for a day, three days, or five days!<sup>11</sup> This curriculum recognizes that adult learners already have a foundation of knowledge and experiences and want new learning to be useful in their daily life. Much of the lesson time is spent in small groups learning from each other; story-telling and reflection are important components. There also may be a national training curriculum that could be used. Fit in with the (organizational) culture. Wednesday afternoons at Malindi Sub-County Hospital there was a continuing education meeting for anyone who was interested – the person in charge was often looking for facilitators to teach sessions and I volunteered whenever there was opportunity. Mentoring is the optimal method of educating those who will be involved in front line care. Make it a point to bring a learner with you whenever you interact with palliative patients, whether it is breaking bad news or doing holistic assessment and treatment. Afterwards, discuss what went well and how you might do better next time, and when the next time comes, let the learner take the lead.

### Implementation Features

Implementation - begin providing services. A listening ear, medications, prayer; whatever is possible, wherever possible, whenever possible. Don't let lack of funds or venue be a deterrent.

Model holistic care, ensuring physical as well as social, spiritual, and psychological care. Meet the needs that you are able to, recognizing that you will not be able to 'fix' everything (or even close to everything), and bring the rest before God.

Work with your team to access appropriate medications. Morphine is important, but if you have access to methadone instead, use that, or codeine, or tramadol, while you work towards finding better opioids. Unfortunately, drug trafficking regulations often make access to morphine and other narcotics problematic. However, with patience, advocacy, and continued relationship-building you may be able to make progress. The WHO has a list of Essential Medicines in Palliative Care with their indications and dosages that can be tailored to local needs.<sup>12</sup>

When there are insufficient local policies, address the issues and work together to create the appropriate policies to allow you to move forward. The issues we encountered mostly involved the access, reconstitution, and appropriate storage and dispensing of morphine. Over many months of meetings with the Medical Superintendent, head pharmacist, and hospital Matron, the palliative care committee crafted policies that worked for the hospital, the palliative care department, and the patients.

Recognize that God brings opportunities and resources. From the beginning it was my prayer to see this initiative at the grassroots community level, and have an emphasis on spiritual care. A local Catholic nun who was a nutritionist and ran a community health worker (CHW) program was visiting at the hospital, heard about palliative care, and requested that we teach palliative care to their CHWs. In this way palliative care was integrated into the CHWs' activities and an understanding of palliative care began to take root in the community. A priest who had been trained in Clinical Pastoral Education and had a vision to train other spiritual leaders approached us about working together and we were able to teach about palliative care in their training. Calvin College sends summer interns to

developing countries to do research, and one worked with us to determine community perceptions about end of life. She asked the communities about their current practices, what was good and what they would like to see improved. This helped the palliative care team understand what kind of educational material they needed to develop to fill the gap.

As the program grew, God, in his timing, also provided material needs. The Kenya Hospice and Palliative Care Association had successfully lobbied the government to put palliative care on its list of essential services, so the sub-county hospitals were mandated to begin offering palliative services and the hospital provided a furnished building for palliative care services along with a supply of medications. Two very capable nurses found sponsorship to take a modular two-year Higher Diploma in Palliative Care. They then took the lead in the Malindi Sub-County Hospital Palliative Care department, one in inpatient care, and the other in outpatient care and training.

### Palliative Care Now

I left Kenya in 2014. What is happening with the initiative today? In an official capacity, not very much. There have been very rocky times recently in the health sector in Kenya. In late 2016 and early 2017 there was a 100-day doctors' strike, and shortly thereafter a prolonged nurses' strike began which is ongoing as of October 2017. Although no new palliative patients have been assessed for many months and the previous structured palliative care program is no longer functioning at present, its impact is still felt, to a large extent due to the TD method of implementation. Palliative patients who were receiving morphine for their pain are still able to collect it from the hospital pharmacy – the head pharmacist was an enthusiastic member of the palliative committee. One of the nurses with a higher diploma in palliative care has left the public sector and is now a Nurse Manager at a new private hospital in Malindi and carries her experience and training

with her. The other nurse is still enthusiastic about palliative care and is looking forward to resuming her role when the strike is over. Many Clinical Officer and Medical Officer interns have moved on to new positions in the country and likewise use their palliative training wherever they are; one was hired by the palliative care program in Mombasa, 120 km from Malindi. And Community Health Workers now have tools to help when their community members face death. Not long after the CHW training, some visiting nursing students accompanied a CHW supervisor on a home visit to a 27 year old mother of 5 children with end stage esophageal cancer, lung metastases and a tracheo-esophageal fistula. They watched in awe as he asked pertinent questions about the effectiveness of the patient's medications for pain and shortness of breath, then skillfully addressed the psychosocial and spiritual issues of the family – how was the husband coping emotion-ally and financially? What were their spiritual resources? Her husband was battling with burdens of guilt, uncertainty, and feelings of inadequacy. After praying a blessing on the household and asking God to be present during this dark time, the CHW supervisor made arrangements to follow up closely with the whole family – the wife with her palliative care needs, the husband who was about to be bereaved, and the children whose swollen bellies and rust colored hair betrayed their precarious nutritional status.

God is at work and through palliative care we are privileged to join him in relieving suffering and restoring relationships and mentoring others to do the same. As we faithfully offer up to him our skills and abilities, he uses us to bring healing, sometimes physical, sometimes psychosocial, and sometimes spiritual.

### References

1. World Health Organization. Definition of Palliative Care. Available at <http://www.who.int/cancer/palliative/definition/en/>



2. World Vision [Internet]. Johannesburg: Campaigns and Projects / Transformational Development; c2017 [cited 2017 Nov 05]. Available at: <http://www.worldvision.co.za/campaigns-projects/transformational-development/>
3. Meyers B. *Walking With the Poor: Principles and Practices of Transformational Development*. New York: Orbis; 1999. pp. 2,15.
4. Corbett S, Fikkert B. *When Helping Hurts: How to alleviate poverty without hurting the poor and yourself*. Chicago: Moody; 2009. pp. 56-62,136-138,125-130, 144.
5. Kumar S. Community programmes in palliative care: What have we learned? *Indian J Palliat Care*. 2005 ;11:55-7. Available at <http://www.jpalliativecare.com/text.asp?2005/11/1/55/16648>
6. Stjernswärd J, Foley KM, Ferris FD. The Public Health Strategy for Palliative Care. *J Pain Symptom Manage* 2007 May;33(5):486-93. <https://doi.org/10.1016/j.jpainsymman.2007.02.016>
7. Davaasuren O, Stjernswärd J, Callaway M, Tsetsegdary G, Hagan R, Govind S, et al. Mongolia: Establishing a National Palliative Care Program. *J Pain Symptom Manage* 2007 May;33(5):568-572. <https://doi.org/10.1016/j.jpainsymman.2007.02.017>
8. Stjernswärd J, Ferris FD, Khleif SN, Jamous W, Treish IM, Milhem M et al. Jordan palliative care initiative: a WHO Demonstration Project. *J Pain Symptom Manage* 2007 May;33(5):628-33. <https://doi.org/10.1016/j.jpainsymman.2007.02.032>
9. Brown S, Black F, Vaidya P, Shrestha S, Ennals D, LeBaron VT. Palliative care development: The Nepal model. *J Pain Symptom Management* 2007 May;33(5):573-7. <https://doi.org/10.1016/j.jpainsymman.2007.02.009>
10. Lavy V, Bond C, Woolridge R. *Palliative Care Toolkit*. Worldwide Hospice Palliative Care Alliance. London 2016. Available from: <http://www.thewhpc.org/resources/item/palliative-care-toolkit-2016>
11. Lavy, V. *Palliative Care Toolkit Trainer's Manual. Help the Hospices*. London 2009. Available from: <http://integratepc.org/wp-content/uploads/2012/12/Pall-Care-Toolkit-Training-manual-FINAL.pdf>
12. World Health Organization. *Essential Medicines in Palliative Care*. 2013. Available from: [http://www.who.int/selection\\_medicines/committees/expert/19/applications/PalliativeCare\\_8\\_A\\_R.pdf](http://www.who.int/selection_medicines/committees/expert/19/applications/PalliativeCare_8_A_R.pdf)

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