ADVOCATING FOR PAEDIATRIC PALLIATIVE CARE NEEDS THROUGH THE DEVELOPMENT OF SOCIAL NETWORKING SKILLS IN SOUTH AFRICAN HIGHER EDUCATION

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Abstract

The integration of Paediatric Palliative Care (PPC) within the social services qualifications is part of new development in education, but for the practice impact required, this space needs to benefit of a tried and tested framework on environmental networking, that may be at risk of only being seen as part of earlier innovation. Building from known insights on the integration of the sustainable development goal of building partnerships into the curriculum, focus will be provided on social networking skills from a person-environment perspective. Considering the risk to terminally ill children when sufficient partnerships are not in place, as required by the 17th sustainable development goal, a case is made for the use of a deeper understanding of the environment and the strengthening of support structures through social network analysis and environmental modification.

Keywords: Social network analysis, paediatric palliative care partnerships, environmental modification.

1. Introduction

UNICEF supports and encourages governments to focus on five specific asks for the implementation of global partnerships for sustainable development, with children needing to be at the centre (UNICEF, n.d). While South Africa (SA) is a signatory to the United Nations Charter on the Rights of the Child, underwriting the right for children to the highest possible standard of health and access to health and medical services through article 24 (UNICEF, 1990), a concerning lack of alignment between policy and funding for Paediatric Palliative Care (PPC) exists in SA. Of interest for this article is the 17th sustainable development goal (SDG17) that calls to strengthen the means of implementation and to build and enhance partnerships with diverse stakeholders (UNICEF, 2022). Results from a case study done with a child and youth care centre (CYCC), described in more detail and within another context in Swanzen (2022), also indicated a lack of sufficient partnerships to meet the needs of terminally ill children. This lack was evident in the poor access to quality and emergency health care, without significant expenditure, for which funding models across health and social service departments are not integrated and responsive. This raises the level of concern regarding children's rights, since an average of 75% of child-related SDG indicators in every country by 2019, either had insufficient data or showed insufficient progress to meet SDG targets by 2030 (UNICEF, n.d). Against the backdrop of grassroot challenges caused by CYCCs not receiving support for PPC, the need for social networking skills (in the context of the person-in-environment framework) to be developed as a community level solution, will be unpacked in this paper. The environmental modification enabled through these skills will address at least three of the key asks for with SDG17. Some studies like one at the Universitat Politècnica de València (Leiva-Brondo & Lajara-Camilleri, 2022) confirms that after activities related to sustainable development goals within subjects had been performed, students' awareness and literacy of sustainability improved. Similarly, an intentional focus on and organisational endorsement of the development of social networking skills, are believed to be part of the capacities to be leveraged to strengthen PPC service delivery.

From the author's own experience, a fitting part of foundational social work knowledge base exist around environmental intervention, but from a source that has not been updated through subsequent editions. A search for literature sources incorporating this framework for inclusion in the curriculum was found to be limited, motivating the attention drawn to this valuable tool through this paper. The few literature sources that touch on this framework, as references in this article will show, presents an absence of the previous American authors who published on this. The main source used in the next part have been

deemed too old to include in curriculum design and its full replacement has proofed to be difficult. Not only will searches on social networking cross-over to internet-based social media concepts that become relevant for marketing strategies and public trust (Sadiku, Omotoso & Musa, 2019; and Paskarina, 2023), it is also presented as social networks or maps (what) only and not the skill of social networking (how). There are some promising applications of social network analysis in health (McKinlay; McDonald; Darlow & Perry, 2017; Fortea-Cabo & González-Teruel, 2022; and Mukinda, Van Belle & Schneider, 2022) and social psychology (Butts, 2008). The usefulness of the social network analysis practice tool to comprehensively evaluate partnerships needed to support critical PPC services, will be explained, an intervention that will be more cost effective than just considering the high individual, medical care costs typically involved.

2. Proposed conceptual framework to address partnership goals

Because of the purpose of this paper, the interrelated concepts of sustainable development goals, PPC support and social networking will be highlighted, but most of the focus of the paper will be on the latter. This is to provide a more recent reference to a tool that has found relevance, but have not had sufficient backing through textbook publications, which risks its place in the social sciences curriculum.

2.1. Building partnerships for sustainable PPC

"Palliative care is a key facet of high-quality pediatric … care as it addresses physical symptom burden, goals of care, advance care planning, medical decision making, and end-of-life (EOL) care" (Massie, et. al., 2021: 452). An important link between SDG17 and PPC, therefore lies in the economics of PC and how this impacts on the quality of care required. The European Association for Palliative Care (EAPC) presses acknowledgement of the cost of EOL care, since out-of-pocket, higher medical expenditure increases the poverty trap, while sufficiently trained psychosocial professionals advocating for and identifying responsive networks are critical in the reduction of this cost (EAPC, 2022). On the economics of PC, the EAPC (2022) emphasised the return on investment to have already show promise and that PC enabled 85% of patients and families to spend less on medicine, which is significant if one considers that caregivers often lose their income while caring for terminally ill family members. The World Health Organisation and partner organisations published a number of documents on models of care to guide wider roll out of PC services, which discussion falls outside the scope of this paper. Specific advancement in the adoption of a rural model was presented by O'Brien et al (2019) who highlighted that in 2015 SA ranked 34th in the Economists 'Quality of Death Index', the highest-ranking African country, and that SA launched the National Policy Framework and Strategy for Palliative Care (NPFSPC) 2017-2022. The NPFSPC prioritises PC and training of health workers involved in PC, with emphasis on addressing issues of universal health coverage and the need to reduce suffering and promote development and dignity for all (O'Brien, et al). Considering that the training of social workers (SW) and child and youth care workers (CYCWs), the two recognised professions delivering social services to vulnerable populations in SA, hold the knowledge base and skill in working in resource constrained communities, which can reduce high medical EOL cost, it is critical to ensure their contribution to PPC is exemplified. Strong assessment information is required to facilitate improved partnerships and the next sections aim to demonstrate the detail required for understanding the environment context of potential partnerships.

2.2. Environmental assessment and the 'key asks'

Easing towards an understanding of social network analysis, the environment and the SDG17 asks will be touched on in this section. It is firstly worthwhile to note the allowance provided for alignment with the quintuple helix as a visualisation for the collective interaction and exchange of knowledge. According to Schocair, Dias, Galina and Amaral (2022) the *quintuple helix* includes the university as a leading sphere to generate knowledge and technology at the same industry and government level, including the influence from actors of the organised civil society, and consideration of the environment and sustainability. For the author this is further support for why higher education (HE) needs to ensure that community-level practice models remain relevant within especially the curriculums preparing social service professionals. This multi-level engagement is more likely to lead to advocacy for the meeting of PPC needs in resource-restrained settings such as CYCCs.

Key asks for SDG17 are to build, strengthen, and expand partnerships; broker meaningful multi-stakeholder coalitions and alliances; engage with the UN system as key partner; enhance North-South, South-South, horizontal and triangular cooperation; and leverage and pool resources, capacities, technology and data (UNICEF, n.d). It is evident why expertise in being able to analyse the environment towards networking is critical. Universally needed environmental resources include adequate social support systems, access to health and day care services and recreational facilities, mobility to

socialise, utilise resources and exercise rights as citizens, adequate housing, police and fire protection, sufficient nutritional intake, predictable living arrangements with caring others, opportunities for education,

self-fulfilment and employment, and access to legal resources and religious organisations (Kemp, et.al, 1997). Needs-driven assessment remains one of the key drivers for relevant service delivery in the social service sector and parallel to this should be an understanding of the context of the lived settings of clients.

The environment is defined as having physical, cultural and social spaces and are described as follows (Kemp et al, 1997): the *physical* environment comprises of the natural world and the built world; the *social* environment comprises the network of human relations at various levels of organisation; and the *cultural* space is influence by both the physical and social environments, and incorporates values, norms, knowledge, and beliefs. Adding the multidimensional entities of the perceived environment (individual and collective systems of meaning and belief); the institutional and organisation, and socio-political environments, a comprehensive foundation is set for environmental assessment. Environment assessment EA) is defined as "an ongoing process in which client and worker, in partnership, gather and critically analyze information on the client or client system, in transaction with multiple levels of the environment, including strengths, resources, potentialities and opportunities, as well as risks, challenges, and issues of concerns, and with the attention to the meaning of these environmental experiences for the client" (Kemp, et.al, 1997, p. 85). Table 1 provides a summary of various EA tools and methods. The horizontal headings indicate the types of environments and vertical are the client system types.

Table 1. Environmental Assessment (EA) tools and methods.

Client system	Perceived	Physical	Social / Interactional	Institutional / Organisational	Social-political / Cultural
Individual	Perceived support network inventory Multi-dimensional scale of perceived social support Socio-political control scale	Assessment of universal resources EA Index PIE system	Social Network Map Ecomap Community Interaction Checklist PIE system	Ecomap Nurturing / Sustaining Environment PIE system	Culturalgram Power analysis
Family	Family support scale Narrative techniques	Family access to basic resources Family resource scale	Ecomap Inventory of social support	Ecomap Family Empowerment scale	Cultural Genogram Power analysis
Group	Ethnographic interviewing Participant observation	Participant observation	Sociogram Socio-environmental context of group	Context diagram of environmental transactions Force field analysis	Power analysis Nurturing / Sustaining Environment
Neighbourhood	Organisational history of neighborhood Participant observation	Physical description of neighborhood	Nomothetic ecomapping	Capacity inventory Inventory of local associations Community inventory	Framework for conceptualising community Power analysis

Kemp, et al, (1997, p. 122)

2.3. Social network analysis skills

A social network is defined by a set of entities with a social relation in those entities, and the network is bounded by the set of entities on which it is defined (Butts, 2008). As a principle applying to any social grouping, network boundaries are of particular importance due to the intrinsically interactive nature of relational systems (Butts, 2008). The root of social networking being the start of environmental intervention, lies within person-environment practice purporting the following building blocks (Kemp, Whittaker & Tracy, 1997, p.4-6): partnership between clients and professionals, meeting on common ground as a unified team; mutuality where an open atmosphere is created for communication about sensitive concerns, built on mutual respect and trust; reciprocity in the helper-principle where giving and receiving help go both ways among all key players; social assets is where the assessment begins with looking at what is going wrong (deficits) and also what is going right (strengths); being alert to *resilience* as protective factors and mechanisms that blunt the effects of known risk factors and permit individuals and families to overcome extraordinary difficult life situations; *optimisation* as the goal to always create conditions within which each individual client, family or neighbourhood reaches the upper limit of its developmental potential; *natural helping* draws on the ability of clients and communities to aid themselves through ritual, spiritual practice, celebration and reflection; *social integration* involves working with 'private troubles' of clients in the context of raising public concern about the critical integrating function of individuals, families and neighbourhoods in maintaining social order and

promoting public safety, and thereby removing risk and change the environment; *coherence* describe processes through which the individuals, families and groups discern a sense of meaning beyond the struggles of day-to-day existence; and the fostering of *hope* that things can change for the better and that the power for change resides within.

From the building blocks of person-environment practice it is important to also have a deeper understanding of the environment, for which ecological systems theory has a lot of utility. Especially its building from Bronfenbrenner's basic concept that an individual's social field increases concomitantly with his or her overall development and the value of highlighting the transactional space of increasing personal competencies to deal with environmental blocks (Kemp, et al, 1997). Believing however that ecological system theory alone does not offer panacea, these authors expanded to social networks (the structure and number of a person's social relationships) and social support (exchanges within the network). Social support can occur through natural helping networks or can be professionally designed or mobilised, noting that more social network resources does not necessarily imply more social support (Kemp, et al, 1997). "Accurate, multidimensional, and textured information on neighborhood environments is an essential foundation for practice that incorporates a community perspective" (Kemp, et al, 1997, p. 76). When resilience, protective factors and environmental risks are added to the mix towards comprehensive social networking analysis, it will incorporate individual attributes, family or interpersonal factors, and community or neighbourhood factors (Kemp et al, 1997). The social network analysis starts with guiding questions to the clients to develop a social network map, after which the social network gird in Table 2 gets completed (Kemp et al, 1997). The top 15 people in a network is used, so the grid will normally have 15 lines.

Table 2. Social network grid.

Respondent	Area of life Household Other family Work/school Organisations Other friends Neighbours Professionals Others	Concrete support 1. Hardly ever 2. Sometimes 3 Almost always	Emotional support 1. Hardly ever 2. Sometimes 3 Almost always	Information / advice 1. Hardly ever 2. Sometimes 3 Almost always	Critical 1. Hardly ever 2. Sometimes 3 Almost always	Directions of help 1. Goes both ways 2. You to them 3 Them to you	Close-ness 1. Not very close 2. Sort of close 3 Very close	How often seen 0. Not see 1. Few times p/y 2. Monthly 3 Weekly 4. Daily	How long known 1. Less than 1yr 2. 1-5 yrs 3 More than 5 yrs
1									
2									
3									
To 15									

Kemp et al (1997, p 111)

In addition to the specific variables, assessment information from the other tools from Table 2, will assist the worker to understanding culturally specific patterns of help-giving, identify sources to aid in the maintenance of intervention gains, understand family system boundaries, pinpoint sources for conflict within the personal network, appreciate the client's perception, and encourage the client to actively restructure the immediate social environment (Kemp et al, 1997). Thorough assessment paves the way for effective intervention.

3. Environmental intervention

Environmental intervention is "both action in the environment and the process of transforming individual and collective perspectives through critical analysis of the impact of environmental conditions" (Kemp et al, 1997, p. 136). Core practice activities include gaining access to, developing and enhancing resources and services, including social networks that support, educate and empower clients and communities, and working to change toxic and oppressive environmental conditions (Kemp, et al, 1997). The eventual goal is twofold: to create an environment that nurtures and support growth and change, and to enhance individuals and groups' abilities to act in the environment on their own behalf (Kemp et al, 1997). Social network strategies towards environmental modification involve the four major approaches of natural-helper interventions, network facilitation, mutual aid or self-help, and social network skills training (Kemp, et al, 1997). One example of structural change under social network skills training, is to increase or decrease the size of the network, or to change its composition or frequency of contact, while an example under network facilitation, can involve the teaching of reciprocity skills, so individuals can act assertively when their rights aren't respected (Kemp et al, 1997).

4. Conclusion

Community work in SA is influenced by the sustainable livelihoods model. While its nature cannot be covered in this paper, this is another approach that requires the skills discussed in this paper, as is also the case for Community Profiling. While this article cannot cover more detail on the strategies discussed, a case was made for the importance of not losing the roots of analysing and intervening in complex environmental matters. Environment intervention is more than community work with impoverished communities. The individual's interaction with their environment is one of the strongest predictors of their quality of life. This link becomes even more critical when it comes terminally ill children and their families trying to navigate EOL needs.

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