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Title: A critical rejoinder to “Life’s end: Ethnographic Perspectives”

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ABSTRACT

This article stands as a response to Goodwin-Hawkins and Dawson's (2018) article "Life's End: Ethnographic Perspectives" which was published in this journal as an Introduction to a Special Issue of ethnographies about end of life. We address three interwoven fallacies promoted in "Life's End." First, we begin by challenging the authors' central contention that there is no "rigorous body of anthropological work on the issue of dying." We then problematize the authors' conflation of anthropology and ethnography. Finally, we deconstruct their argument that there is an "anthropological aversion" to the study of dying stemming from the inherent "intimacy" of ethnographic methods, as well as their assumption that there is something uniquely emotionally challenging about studying dying. We argue that in framing their Introduction to ethnographies of dying as largely one of absence, Goodwin-Hawkins and Dawson ignore a rich history and diversity of research. In challenging the authors' obfuscation of our subdiscipline, we offer as a corrective a wide range of examples taken from a substantive canon of ethnographic research spanning almost 70 years. We conclude with a broader call for slow academia to ensure that important scholarly contributions are not erased from memory and history rewritten.

Introduction

In this article, we offer a critical rejoinder to an argument put forward by Bryonny Goodwin-Hawkins and Andrew Dawson (2018) in an article published in this journal entitled "Life's end: Ethnographic Perspectives". Their article acts as an Introduction to a Special Issue comprising eight articles on ethnographic studies of dying. The central argument advanced by the authors is that while anthropologists have had a long-standing interest in death, dating back to Malinowski (1916), there is a dearth of anthropological interest in and research into dying—or as they put it, "life's end." They claim to have come to this conclusion after a review of the

field. As anthropologists who have studied death and dying for many years, we find a good reason to challenge this central argument. We are disquieted by the factual inaccuracies evidenced in the article, and in our considered response we outline numerous flaws in the authors' line of argument. Many of the inaccuracies stem from a seeming failure to review the literature, as there is a substantial and influential body of work. Our aim is for this article to stand as a corrective to three interwoven fallacies promoted in "Life's End." The first fallacy is that anthropologists have not been interested in, or published significant work on, human dying. The second fallacy is the implicit assertion that ethnography resides predominantly in the domain of anthropology. The third fallacy is that, as a method, ethnography necessarily engenders emotional intimacy with participants which is heightened in the context of studying dying, and acts as a deterrent to ethnographic research on the topic.

Our own background as anthropologists working in the field of death and dying is significant in our claim to considerable expertise and thus worth outlining at the outset. Krawczyk (2015, 2019) trained as an anthropologist in Canada and has herself conducted an ethnographic study of hospital dying. She is also undertaking a genealogical review of hospital ethnographies in order to explore how cultures of Western medicine have, and continue, to organize the end of life. Richards (2012, 2017) trained as an anthropologist in the UK and conducted an ethnographic study of Britons traveling to Switzerland for an assisted suicide. She is currently engaged in a project on the effects of socio-economic deprivation on experiences of dying. Both Krawczyk and Richards have also taught university courses on death and dying, which involved introducing students to the anthropological "canon." Our own work builds on the legacy of existing scholarship, which prompts us to ward against the historical erasure of a rich and diverse body of anthropological work on dying. In this article, we make visible the canon, as

we see it, not solely in order to “set the record straight,” but because, we argue, it is only in reading and engaging in the contributions of scholars who come before us that we can avoid reproducing work which has already been done or claiming gaps or novelty where indeed there is none.

There is no rigorous body of anthropological work on the issue of dying

The authors’ first claim is that while there is a robust body of literature on the anthropology of death, this has occurred “at the expense of developing a more rigorous body of anthropological work on the issue of dying.” We are unclear as to the basis of this assertion, as even a cursory search evidences a long lineage within anthropology, covering a range of care settings, concerns, and geographies. A particularly well researched aspect is end of life within hospital settings. Notable examples include Sharon Kaufman’s (2005) award-winning ... *And a Time to Die: How American Hospitals Shape the End of Life*, which ethnographically mapped how we paradoxically both turn to and away from technology at the end of life, and the resulting liminality between life and death—or what Kaufman calls “zones of indistinction”—which emerges as a consequence. Helen Stanton Chapple’s (2010) *No Place for Dying: Hospitals and the Ideology of Rescue* provided significant insight as to how the entrenched ideology of rescue in American hospitals shapes care pathways even for those who have no foreseeable prospects of survival.

Ethnographic interest in end of life was also evident before the turn of the century. A particularly well-known example is Myra Bluebond-Lagner’s (1978) enduring American classic *The Private Worlds of Dying Children*. Her research explored how children with terminal leukemia come to know that they are dying when no one tells them, and how they conceal their knowledge from their parents and medical staff. Through the use of play therapy, observation,

and conversation over 9 months with 40 children aged three to nine years in a Pediatrics Department of a large Midwestern teaching hospital, Bluebond-Langer found that children's awareness of their impending death evolved through a step-wise progression of interpreting social, contextual, and physical cues. Their terminal illness, she found, threatened everyone's ability to fulfill socially defined roles: the doctors' ability to identify as curative agents; the parents' identity as nurturers and protectors; and the assumption that children necessarily have a long future ahead of them. Conscious that their own awareness of dying threatened these roles, and wanting to maintain membership within this society, the children hid their awareness from parents and caregivers. "The way we are permitted to die, and the way we permit others to die" she argues, "is to enable the living to continue the processes of their lives ... [as] dying is an antisocial act" (p. 233). Bluebond-Langer's ethnography radically challenged the prevailing ideology that terminally ill children do not have the intellectual and emotional capacity to independently "know" they are going to die. One of the lasting legacies of this ethnography was the innovative structuring of fieldwork notes as a five-act play, which both develops and reflects the children's five-stage socialization process from diagnosis to death, and which provides an immersive experience into the everyday life worlds of terminally ill children. Another example from that time period is Carol Germain's *The Cancer Unit: An Ethnography* (1979) which provided insight into the emerging professionalization of advanced cancer nursing, including how it shapes care for those at end of life.

Book-length ethnographic investigations by anthropologists about end of life in hospitals are not limited to North America. In *Negotiating a Good Death: Euthanasia in the Netherlands*, Robert Pool (2000) explored how hospital doctors and patients negotiated complex decisions about euthanasia during an advanced terminal illness. Joan Cassell (2005) conducted fieldwork

in ICUs in New Zealand as well as in the USA, resulting in *Life and Death in Intensive Care* which explored the “moral economies” shaping end-of-life decision-making in these settings, including economic considerations, bureaucratic constraints, and conflicting professional ideologies. In Australia, Beverly McNamara (2001) used ethnographic methods to produce *Fragile Lives: Death, Dying, and Care* which shone a spotlight on the ways in which increasing medicalization and bureaucratization of palliative and hospice care shifts focus from a “good” to a “good enough” death, with clinicians concerned primarily with effective physical symptom management. In *Final Days: Japanese Culture and Choice at the End of Life*, the anthropologist Susan Orpett Long (2005) detailed how patients, family members, and medical staff negotiated multiple—and at times conflicting—cultural scripts within end-of-life decision making and beliefs about what constitutes a “good” death. More recently, Julie Livingston’s (2012) *Improvising Medicine: An African Oncology Ward in an Emerging Cancer Epidemic* included substantive ethnographic detail about both living with and dying from cancer in the shadow of the AIDS epidemic in Botswana.

Other anthropologists have ethnographically attended to “life’s end” within quasi-community settings such as hospice and residential care. Thirty years ago, Jennifer Hockey (1990) in *Experiences of Death: An Anthropological Account* used ethnographic fieldwork within residential care homes and hospice in the UK to explore how the “slow deterioration of old age” problematizes cultural norms that maintain distinct boundaries between life and death. In Germany, Nicholas Eschenbruch (2006) produced an ethnographic study of meaning and autonomy in hospice care, framed through his experiences as a nursing assistant. Perhaps best known in this category is Julia Lawton’s (2000) classic ethnographic monograph *The Dying Process: Patient Experiences of Palliative Care*, where she analyzes how hospices in the

UK are containers for particular types of “dirty dying” the rest of society does not want to see. Conducted over the course of 10 months, Lawton came into contact with 280 patients, and 200 deaths occurred in the hospice during her fieldwork. Through vignettes of individual patient’s experiences, she reveals the realities of patient’s bodily deterioration and decay—what she terms their “unbounded, leaky bodies” (p. 142). She sums up the feelings of the patients she encountered as those of “dull resignation; of apathy, lethargy and exhaustion; of finally giving up” (p. 80). This apathy she chalks up to their declining ability to act in embodied ways. From these insights she develops a theory of the Western self, which she argues is based on being able to bodily enact one’s own wishes and intentions, as well as maintain control of the physical boundaries of one’s own body (p. 165). Lawton’s monograph has become an important contribution to understanding what happens when the dying body becomes unbounded, and how that unboundedness, as well as the inability to time death, affects relationships. Her work is also significant because it provided new insights into how dying, specifically within the institution of the hospice, does not always conform to romanticized notions and can be traumatic for the reasons outlined above. Finally, there are anthropologists who ethnographically map the felt experiences of terminally ill people as they move through a myriad of care settings at end of life, such as Anne-Mei The’s (2002) *Palliative Care and Communication: Experiences in the Clinic* which mapped, over five years, Dutch patients’ and family members’ attempts to sustain optimism as they journeyed from diagnosis of bronchial and lung cancer through to death. These myriad examples are not offered as an exhaustive list, but rather to evidence an established, substantive, and rigorous anthropological canon of ethnographic research that is well-referenced among those of us who research end of life. If we were to add to the above monographs peer-reviewed journal articles by anthropologists concerned about “life’s

ends,” the field of literature becomes truly enormous. We therefore leave readers to undertake this review work on their own. However, even as we have enumerated key monographs to refute Goodwin-Hawkins and Dawson’s claim, we are also aware that doing so replicates the problematic division constructed by the authors between the use of ethnographic methods in anthropology and in other disciplines, most notably sociology.

Ethnography is only utilized by anthropologists

Goodwin-Hawkins and Dawson (2018, p. 270) state that “investigation of dying has, by and large, a richer pedigree in other disciplines, such as sociology and, most notably sociological studies of palliative care in particular”. To bolster this assertion, they cite somewhat odd exemplars—two targeted literature reviews undertaken in service of developing standardized definitions within medical practice, both well over a decade old, and neither describing their methods or approach as sociological. We are surprised at the authors’ choice of these articles as evidence of this “richer pedigree” in lieu of any reference to a well-known body of sociological research that spans nearly 70 years. We also take issue with the authors’ implicit fusion of ethnography to anthropology, thereby rendering invisible the entwined lineage between anthropology and other disciplines—both methodologically and theoretically—and in particular, sociology. In the following section, we reference a range of monographs by sociologists to demonstrate how even a cursory reading of this literature clearly evidences that the characteristics of ethnography, as defined by Goodwin–Hawkins and Dawson, are clearly evident in these works. We also offer these examples to highlight that many of the authors have explicitly specified their methodological approach as ethnographic.

More than 50 years ago, the sociologists Barney Glaser and Anselm Strauss gained worldwide recognition—both within and outside their field—for their ground-breaking

monographs *Awareness of Dying* (Glaser & Strauss, 1965) and *Time for Dying* (Glaser & Strauss, 1968). These books were the result of a multiyear fieldwork study of the social organization of care work and communication with terminally ill patients in six hospitals in the San Francisco Bay area. While it remains unclear how much time these two authors actually spent in the field themselves, they employed numerous assistants to conduct “field observation” (p. 266). Their findings, including the development of foundational concepts such as “awareness contexts,” “dying trajectories,” and “sentimental work,” were grounded in real-life experiences of clinical staff, patients, and family members, and even today remain central to the development and provision of care for those nearing end of life. In the same era, David Sudnow (1967) published *Passing On: The Social Organization of Dying*, which he defined as “first and foremost an ethnography” (p. v), focused on the ways in which routine hospital work organized dying. Through his fieldwork over a year and a half in two different hospitals, which included directly observing more than 200 deaths, he was able to render visible the ways in which the everyday work within specific socioeconomic conditions either facilitated or hindered a patient’s “social death” before their clinical or biological death. Similar to the concepts generated by Glaser and Strauss, Sudnow’s “social death” has been profoundly influential to the provision of end of life care, and in the social sciences more generally. The sociologist Jane Seymour (2001) characterized her research, which culminated in *Critical Moments: Death and Dying in Intensive Care*, as an ethnography of the ways in which ICU clinicians and nurses attempt to navigate “uncertain death at an unknown time” (p. 3) and their challenges to align physical (“bodily”) and clinical (“technical”) dying.

Examples of sociological monographs that do not explicitly identify as ethnographic but are based on immersive fieldwork and participant observation to elucidate “worldviews” shaping

the end of life include Robert Zussman's (1992) *Intensive Care: Medical Ethics and the Medical Profession*. This book provided a fine-grained analysis of how medical decisions to limit potentially life-prolonging treatment in ICUs are determined by institutional, legal, and biological imperatives often beyond the control of any one individual. There is also David Moller's polemic *On Death Without Dignity: The Human Impact of Technological Dying* (1990), and Renee Anspach's (1993) *Deciding Who Lives: Fateful Choices in the Intensive-Care Nursery* focused on the criteria, processes, and sociohistorical contexts impacting "life and death" decisions in critical neonatal care. We would also be remiss if we did not mention Stephan Timmerman's (1999) excellent *Sudden Death and the Myth of CPR* that examined the ways in which emergency room clinicians categorize and retroactively construct a dying trajectory after unsuccessful resuscitation attempts. Sociologists have also been active in exploring the ends of life in other institutional and community settings, including the ways in which nursing home residents "world build" in the midst of dying, as so evocatively portrayed in Jaber Gubrium's (1975) classic *Living and Dying at Murray Manor*, and the challenges of "disadvantaged dying," such as can be found in Moller's (2004) *Dancing with Broken Bones: Portraits of Death and Dying among Inner-City Poor*.

Our brief overview, which we reiterate is not intended to be comprehensive, evidences that the use of ethnographic methods—as defined by Goodwin–Hawkins and Dawson—to examine "life's end" have been, and continue to be, employed both amongst those who identify as sociologists and those who identify as anthropologists. Further, sociologists interested in dying have long been aware how they have interpreted their fieldwork through reference to anthropological theory (Kellehear, 1984). An early example is Renee Anspach's (1959) *Experiments Perilous: Physicians and Patients Facing the Unknown*, which explored treatment

protocols and prognostic uncertainty within an experimental metabolic unit, and how the shared stresses impacted on doctors and patients. Fox characterized her work as the “first observational sociological study of terminal illness” (p. 9) and drew both from Talcott Parsons’ sociological “role obligations” framework and Malinowski’s anthropological concept of “scientific magic” to frame how social norms of fraternity and the promise of technology worked to alleviate anxieties arising from being on the frontiers of medical knowledge (p. 16). In recounting her fieldwork experiences to the reader, Fox highlights anthropological accounts of participant observation that she drew on to better understand these experiences (p. 235). Another exemplar comes from the anthropologist Julia Lawton, whose work we have already discussed, who drew extensively on the sociological work of Sudnow and his theory of “social death.” These are but two instances evidencing the close connection between different disciplinary approaches to the ethnographic inquiry of “life’s end” and give weight to our assertion that ethnographic approaches are not the sole remit of anthropology or sociology, but employable across a range of disciplines. A particularly clear and early illustration of this entanglement is the previously mentioned *The Cancer Unit: An Ethnography* (Germain, 1979), where the author identifies equally as nurse–anthropologist–researcher, and who characterizes herself as the first to employ the “institutional ethnography” methodology developed by the sociologist Dorothy Smith!

The genesis of ethnography as specific to anthropology implicitly forms a significant aspect of Goodwin-Hawkins and Dawson’s argument. While many credit Malinowski’s (1922) *Argonauts of the Western Pacific* as ushering in contemporary ethnography, it has been a popular method within sociology from as early as 1917, particularly within the famed Chicago School (Deegan, 2001). Further, if we follow Goodwin-Hawkins and Dawson’s (2018, p. 270) definition of ethnography as “long-term immersion” coupled with “participant observation” that enables

representation of “the ‘whole life’ and ‘worldviews’ of particular peoples in particular places ... at particular moments in time” (p. 272) the authors we have cited above have clearly undertaken ethnographies of dying, with many explicitly identifying so. We also note with some irony that in characterizing themselves as working anthropologists aware of the complexities in defining the central method of their field, Goodwin-Hawkins and Dawson choose to reference the work of the well-known *sociologists* Martyn Hammersley & Paul Atkinson. This slippage highlights the many challenges when attempting to differentiate anthropological and sociological methods, and by extension, the disciplinary epistemologies, from one another.¹ The authors evidence further definitional confusion as they acknowledge that two of the eight contributors to their Special Edition are not anthropologists, but rather “draw on anthropological insights.” This contradicts their own apparent stance that only anthropologists can contribute to an “anthropology of dying.” Consequently, while Goodwin-Hawkins and Dawson attempt to delineate between the two disciplines, given their criteria (and definition) of ethnography, we see that this division holds neither “in the field” nor within the authors’ own arguments.

Ethnographies of dying are too emotionally challenging to conduct

Our concern here is to debunk the romanticized view that ethnographic “immersion” necessarily results in feelings of “intimacy” between researcher and participants, as well as the idea that there is something uniquely emotionally challenging about studying dying, compared to all the other spheres of life, and experiences of suffering, which anthropologists choose to study. From the outset, this argument is flawed in a number of respects. To begin with, the authors attribute the view that dying is “too discomfoting and emotionally challenging for the

¹ For example, we note that Atkinson, while currently identifying as a sociologist, has previous degrees in anthropology.

fieldworker” to Palgi and Abramovitch (1984). However, in their review of the anthropological literature of death, Palgi and Abramovitch (1984) make no such claims. In fact, what they argue is that ethnographers might feel a “reluctance to intrude in people’s lives,” which speaks far more to social norms around respecting privacy than it does to researchers wanting to insulate themselves from intense emotions, such as sadness and grief. It is worth quoting Palgi and Abramovitch (1984, p. 385) in full: “It also has been maintained that death is not a central issue for anthropologists because of their natural reluctance to intrude in people’s lives at a time of anguish.” The quote makes plain that Palgi and Abramovitch are referring to studying *death*, and researcher engagement with the bereaved, not studying *dying* or developing intimate relations with people who are dying. It appears that, in this regard, Goodwin–Hawkins and Dawson have themselves conflated death and dying, a distinction which they are at pains to emphasize in their article and which stands at the heart of their argument. This conflation is similarly in evidence in their acknowledgment that Abramovitch’s (2016) blog post on the anthropology of *death* has significantly influenced their article on *dying*.

In terms of the substantive point they make about “intimacy” acting as a deterrent to ethnographic work on dying, we find this to be a flawed argument on three counts. First, Goodwin-Hawkins and Dawson do not define or contextualize ethnographic intimacy, leaving the reader to assume that they refer to close emotional bonds between the researcher and her participants. The presumption that ethnography in general necessary involves, or is predicated on, emotional intimacy between the researcher and her participants, is rather a romanticized one. Ethnographers are not required to share the beliefs of those they study and there are examples of ethnographers studying people whose morality is very different from their own (Ferrell & Hamm, 1998). Ethnographers can be repelled by the actions of the people they study, even as

they value the importance of trying to understand what motivates their beliefs or actions, as was famously revealed in Malinowski's (1967) fieldwork diaries and letters revealing the personal contempt with which he viewed his subjects. Certainly, the immersive qualities of ethnography can help to better understand people's worldviews, but the method does not require emotional intimacy to do this. Far more fundamental to the method are the perceptive qualities of the researcher. Goodwin-Hawkins and Dawson are not the first to assume that ethnography involves emotional intimacy. However, we argue that the danger in making this assumption is that it limits ethnography's capacity to be anything other than that which conforms to a romantic view of mutually appreciative relationships between researcher and researched, akin to something like friendship. Most ethnographers would be the first to admit that undertaking ethnographic fieldwork involves numerous tensions, not least a multitude of conflicting emotions, many of which may be very far from being characterized as giving rise to "emotional intimacy." On the other side of the relationship, participants may not feel particularly intimate with the ethnographer. The public is seldom given an insight into how the "other side" perceives or feels about the ethnographer (c.f. Scheper-Hughes, 2000).

Our second challenge is to the authors' assumption that dying is a special case warranting heightened emotional engagement or risking emotional transference and thereby dissuades anthropologists from undertaking ethnographic fieldwork on this topic. Dying can be traumatic in some cases, both for the dying individual and those around her, including the ethnographer, as Lawton (2000, p. viii) found during her fieldwork: "I spent a great deal of time in close emotional and physical proximity to patients and their families. I grew very fond of some patients and their deaths, though anticipated, were often a source of great sadness and loss." By her own account, Lawton experienced considerable emotional impacts due to witnessing these

traumatic cases of bodily dying. However, such emotional responses are not universally experienced. Kaufman (2005, p. 15), for example, reflects that while she was empathetic towards her participants and the situations they were facing: “My empathy could only go so far because I lived outside their experience and suffering and nothing was presently at stake for me [...] I could not share the intensity of their feelings.” Kaufman goes on to write that when she told people about her research topic, they assumed it must be “depressing.” However, contrary to such expectations, she found that the “analytic challenge” was enough to temper her own fears and sense of horror at the various diseases and treatments she encountered: “Most importantly, I was observing strangers. I had no special bond with any of the patients or families, nor was I acquainted with any of the hospital staff before my research began. Because I was emotionally detached, watching hospital activity did not depress me” (p. 16). This comment by one of the preeminent ethnographers of dying flies in the face of the idea that emotional intimacy is necessary for undertaking ethnographic research with dying people, or that it is somehow an unavoidable consequence of such research.

We acknowledge that anthropologists have long been drawn to the “suffering subject” (Robbins, 2013), studying all manner of social contexts where structural inequalities cause people immense and often inescapable suffering. While there may be a debate within the discipline as to why the “suffering subject” is so compelling (rather than, for example, studying well-being and happiness (Thin, 2008)), there is no doubt that this has historically been, and continues to be, the case. It could well be argued that suffering is far more “emotionally challenging” to study than dying, unless of course, the authors assume that dying always entails suffering or a particularly appalling form of suffering, which is empirically not the case. In this regard, we strongly challenge the view that studying dying is *exceptionally* emotionally

challenging, above and beyond studying suffering induced by psychological trauma, state violence, and extreme poverty.

The fact that anthropologists have long been drawn to studying and writing about the “suffering subject” leads us to our third and final point regarding the emotional intimacy involved in studying dying. We argue that, in certain instances, it may be the potential emotionality of the encounter which has drawn anthropologists to study the topic, rather than an “aversion” to it, as Goodwin-Hawkins and Dawson claim. In a compelling article on this very topic, Hockey (2007) argues that one motive for researchers being drawn to this field of study is to try to make sense of their own personal, emotional, retrospective or prospective experiences of death, dying and bereavement. And we all have them. Given the universality of death, most researchers enter the field with prior experiences of death and grief. The issue for some researchers has been how much to acknowledge those experiences or their own anticipation of death that they bring with them to the field (Woodthorpe, 2011).

In sum, we argue that emotional intensity is neither a pre-requisite for, nor acts as a deterrent to, ethnographic research into dying. The analytic challenge of all ethnographic research, not just research into experiences of dying, is inseparable from one’s emotions about “being a careful researcher” and being sensitive to the consequences of the research endeavor (Kaufman, 2005, p.16).

Conclusion

In this rejoinder article, we have highlighted fundamental flaws in Goodwin-Hawkins and Dawson’s argument that anthropologists have not undertaken ethnographic studies of “life’s end”. We have also offered a number of challenges to the rationale they propose to account for

this (disproven) omission. We have cited bountiful examples of ground-breaking ethnographic works which must be afforded their rightful place in history rather than be subject to erasure. To ignore this work is to do a disservice to our intellectual heritage and the hard work of researchers whose ideas have built the sub-field in which we work. The “canon” has also had real-world impacts and changed medical practices in important ways, further emphasizing the necessity of acknowledging our heritage. We are all too aware of the current pressures within academia to produce work at pace and the temptations this brings to position ourselves as experts across a range of specialisms, necessitating “thin” descriptions. We are also aware of the time commitments involved in undertaking robust peer review. Academic life is arguably now regulated by “the drumbeat of careerism, the relentless marketization of education, and the pursuit of utilitarian efficiency and sheer bureaucratic indifference” (Wilkinson & Kleinman, 2016, p. 193–194). These neoliberalising pressures which can stand at the root of poor scholarship need to be resisted collectively. We stand together with others in championing the value of “slow academia” (Berg & Seeber, 2016); scholarship which prioritizes quality over quantity, and which is, therefore, able to lay solid foundations for future work and generations of scholars yet to come.

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